

RESEARCH COMPONENT

VOLUME I

**THE IMPACT ON PARENTS OF CARING FOR PEOPLE WITH INTELLECTUAL
DISABILITIES AND AUTISM SPECTRUM DISORDER**

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A thesis submitted to the University of Birmingham in partial fulfilment of the requirements
for the degree of Clinical Psychology Doctorate.

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Overview

This thesis is divided into two volumes, a research and a clinical element, which are submitted to the University of Birmingham as a partial requirement to fulfil the Doctorate of Clinical Psychology degree (D.Clin.Psy).

Volume I of this thesis is the research component, which contains three papers. The first paper is a literature review, which explores the concepts and measures used to identify the positive impact of caring for someone with intellectual disabilities. The paper also reviews the relationship between parental wellbeing and positive impact and factors associated to this, including parent gender, syndrome differences and challenging behaviour. The review concludes that a clearer definition and working model of positive impact would be useful in literature pertaining to people with intellectual disabilities. It confirms a relationship between parental wellbeing and positive impact, but other variables affecting this need further research.

The second paper of this volume is an empirical study that explores the relationship between autism spectrum disorder, challenging behaviours and parental stress. The study has two aims, firstly it hypothesises that individuals with autism spectrum disorder who present with challenging behaviour will have more prominent autistic characteristics. Secondly, the relationship between challenging behaviours, autistic characteristics and parental stress is explored. A sample of 51 participants with autism spectrum disorder and their mothers participated in the study. Autistic characteristics and parental stress were assessed via standardised questionnaires. When participants with autism spectrum disorder presenting with challenging behaviours were compared to children not showing challenging behaviours, lower adaptive functioning, interest and pleasure and social and reciprocal

interaction, and higher levels of impulsivity were found in the challenging behaviour group. Age was also found to be a significant variable between groups. Autistic characteristics of adaptive functioning, interest and pleasure, social reciprocal interaction and impulsivity were also correlated to parental stress. A regression analysis determined the only variable to predict maternal stress was impulsivity. The study is unique in its assessment of broader person characteristics. It adds to literature that has begun to recognise impulsivity as a trait that may be contributory to challenging behaviour and predictive of parental stress, amongst other characteristics. Wider research is needed into person characteristics and their relationship to parental stress and challenging behaviour. The paper has been prepared for submission to the journal 'Autism'.

The third paper is a Public Domain Briefing document that summarises the literature review and gives an overview of the empirical study. It aims to summarise main findings for dissemination to a wider audience.

Volume II of the thesis is the clinical component, comprised of five clinical practice reports, which relate to clinical placements completed over three years. These papers include a psychological models paper entitled, 'The case of a 70-year-old man with learning disabilities presenting with a lack of assertiveness: formulations from a systemic and cognitive-behavioural perspective'; a service evaluation entitled, 'Staff perceptions of support offered to family carers and barriers to improvement in a specialist learning disability service'; a single case experimental design entitled, 'An AB single case experimental design; anxiety and depression in an older adult'; a case study entitled, 'A case study of a ten-year old boy with self-harm and perfectionist ideals, with complicating factors of diabetes and coeliac disease; and finally an oral presentation of a case study

entitled, ‘A case study: Molly, a 27-year-old with bulimia nervosa, a Schema Focused Approach’.

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LITERATURE REVIEW

Positive Impact and its Relationship to Wellbeing in Parents of Children with Intellectual Disability

Abstract

Aims: This review focuses on parent carers of children with an intellectual disability. The aims of the review were firstly, to conceptualise themes from qualitative papers that identify positive impact, secondly to identify assessment tools used in quantitative papers that measure positive impact and thirdly to look at the relationship between positive impact and wellbeing in parental carers.

Method: A structured search was conducted in the databases of Psycinfo and Ovid Medline and 24 articles were included in the review. A quality assessment of the papers was completed.

Findings: Fourteen themes conceptualising positive impact arose from the qualitative papers. Themes focused on parental emotion, increased empathy for others, reprioritising life values and an emphasis on the child's achievement. The main measures used to assess positive impact were the Kansas Inventory of Positive Perceptions (KIPP; Behr, Murphy & Summers, 1992) and the Positive and Negative Affect Scale (PANAS; Watson, Clark & Tellegen, 1988). Positive impact was related to a higher sense of wellbeing in parents; however, the exact function of positive impact on wellbeing remains unclear. Positive impact was affected by other variables, including mother father differences, syndrome diagnosis and child challenging behaviour. Variables such as self-esteem and coping strategies also affect positive impact.

Conclusions: A relationship between positive impact and wellbeing exists but remains unclear. Positive impact may act as a buffer against the negative outcomes of caring for an individual with an intellectual disability. A definition and working model of positive impact is absent and further research into positive impact alongside other variables such as challenging behaviour is needed.

1. Introduction

Research into the positive impact on carers of people with an intellectual disability is a small but growing literature (Hastings & Taunt, 2002). This is surprising given the preponderance of family members that undertake caring. The potential for psychological distress in carers of children with an intellectual disability is broadly recognised (Department of Health; DoH, 2008) and accessing services to support health and wellbeing is viewed as a priority (DoH, 2001; 2008). To date, most literature focuses on the psychological impact (Singer & Floyd, 2006; Blacher, Neece & Paczkowski, 2005; Hatton & Emerson, 2003; Blacher & Baker, 2002) and practical difficulties (Davys & Haigh, 2007; Todd & Shearn, 1996; Wodehouse & McGill, 2009; Gilbert, Lankshear & Petersen, 2008; Rogers, 2007; Boyd, 2002) associated with caring for people with intellectual disabilities. However, positive perceptions of caring, which may be an inherent feature of caring, potentially sustaining wellbeing and acting as a motivator for care, appears to have been overlooked in the literature.

The concepts of positive impact and the construct of wellbeing are relatively broad and open to interpretation. This will become evident, especially in the first part of this review. However, for the purpose of the review, these constructs are defined here to enable a broad understanding of these umbrella terms. In this review, positive impact refers to emotions, reflections or relationships that are welcomed, advantageous, beneficial or constructive and occur directly as a result for caring for someone with intellectual disabilities. Examples of this are personal growth for the parent, a change in familial or marital relations and emotions such as love, pride and happiness.

The emotional component of positive impact traverses somewhat with the concept of wellbeing. In this review, the focus on parental wellbeing is measured as an emotional state and will mostly refer to non-preferential states such as stress, anxiety, and depression, but will also refer to potentially more benign states such as level of adjustment. The level of burden a carer feels is also included. Wellbeing in this review is viewed within the context of caring for someone with intellectual disabilities.

When caring for a child with intellectual disabilities, theories of how family systems operate are pertinent. In family systems theory there are three main principles 1) wholeness and order, so that the whole family is greater than the sum of its parts and that the individuals cannot be wholly understood if they are separated, 2) there is a hierarchical structure, so that families are formed by subcomponents, for example a marital dyad or sibling relationships as well as the family place in a wider organisation, such as community, 3) adaptive self-organisation, which is the concept in which systems reorganise in response to external changes acting on the family's internal structure. Adaptive reorganisations may not always make the family system stronger: whilst they may compensate for the change, new vulnerabilities within complex structures may be created (Cox & Paley, 1997; 2003). When the self-organisation system is activated, the system is affected on multiple levels, resulting in changed behaviours and function that eventually cause a feedback loop, offering new patterns in reaction to changing circumstances. Challenges to a family system have been characterised as events such as the departure of a spouse, new birth or premature death (Cox & Paley, 1997; 2003) but this also could be applied to the diagnosis of a disability in the family.

Baum (2006) refers to a family life cycle model (Carter & McGoldrick, 1989) as being a useful way to look at the adaptation and adjustment of families with a child with

disabilities. This is extremely similar to family systems theory, where the focus is on transition stages rather than individual family members, where life cycle transitions create stressors in the system in reaction to which the system reorganises and negotiates change. This can include the birth of a child, beginning school and illness for example. Transitions can be hindered or facilitated by pre-existing family patterns, legacies and family narratives. Family coping ability will be dependent on which life cycle issues each member is experiencing at the time, as transitions will upset the balance in the family and demand change. Baum (2006) emphasises the main stressors in life cycle events on a family with a member with intellectual disabilities are those of being out of synchrony with typical families, grief and loss as previously held expectations are spent, protection of the child with disabilities, parental patterns of relating to the child and the effect on wider support systems.

In Cox and Paley's (1997; 2003) reviews, they note the difficulties experienced in a family with a birth of a child. A new child typically results in a reorganised system with gender roles becoming more traditional, with men and women developing divergent attitudes of themselves as 'parent' and 'worker'. These roles have not necessarily been found to be stronger, moreover they have been found to be a base for increased dissatisfaction and conflict. Some researchers found that families with 'symptomatic children' are characterised by weak marital alliances and cross-generational coalitions or parental coalitions in which 'problem children' are blamed. In addition, research shows that infants who show poorer self-regulation in the first few months, or mothers that are 'insensitive' to their child's needs affect one another, so that a mutual regulation is not encountered (Cox & Paley, 1997). These findings have implications for caring for a child with intellectual disabilities, where gender roles may further be emphasised by the potential

need for a full time carer and where the child with the intellectual disability could be blamed for encountered difficulties in the family. Furthermore, for children with intellectual disabilities who are not able to self-regulate as well as typically developing children, the family may need to work harder to achieve adaptive reorganisation.

In his reflections of raising a child with autism, Holloway (2007) seems to endorse the process of reorganisation when he discusses that the most sought after goal for families may be the wish that the 'illness' in whatever sense may go away. However, families adapt and accommodate their new found status, and there is a new focus on the present. A review of how families with children with intellectual disabilities adjust and adapt have listed a variety of traits and circumstances to make this possible (Kai-sang Yau & Li-Tsang, 1999). This includes personal resources (education, personality, self-appraisal, educational level, financial status and problem solving skills), family resources (family size and form, ethnicity and geographical location), the marital relationship with emphasis on marital satisfaction which is key in determining family susceptibility to disorganisation, team working and having strong sub systems of support, child characteristics (including severity of disability and ability to communicate, gender of child), parent support groups and social resources.

Ferguson (2002) has looked at models of how family systems function when there is a child with intellectual disabilities, from a historical perspective. He concludes that the most popular approach currently utilised is an adaptive model, which is influenced by models of stress and coping. Whilst these theories of family systems functioning focus on processes of change and factors that may contribute to successful change, there is no direct focus on positive impact of this adaptation. This oversight is also evident in the models of

caring for people with intellectual disabilities that Ferguson (2002) refers to as the stress-coping or adaptation models.

Four models of this nature are prominent (Hill & Rose, 2010) in literature pertaining to people with intellectual disabilities. These models are the Double ABCX Model (McCubbin & Patterson, 1983) the Transactional Model of Stress and Coping (Lazarus & Folkman, 1984), a Two-factor Model of Care giving (Lawton, Moss, Kleban, Glicksman & Rovine, 1991) and the Model of Parent-Child Interactive Stress (Mash & Johnston, 1990). These models make little or no mention of positive impact and the processes involved in attaining this. Folkman and Moskowitz (2000) recognise that stress can never be understood fully without recognition “of the other side of coping” (p. 647) and to date there is no widely used model that incorporates positive impacts of caring.

Care giving resulting in a negative outcome, such as stress, does not necessarily mean that positive impact cannot coexist. Positive and negative impacts are viewed as orthogonal variables, which can co-occur, rather than opposite poles on a continuum. This relationship is broadly accepted in literature pertaining to caregivers of people with intellectual disabilities (Hastings & Taunt, 2002), health difficulties (Hunt, 2003; Sanders, 2005; Leipold, Schacke & Zank, 2006; Kim, Schulz & Carver, 2007), dementia (Peacock et al., 2010) and older adults (Yamamoto-Mitani et al., 2004; Cohen, Colantonio & Vernich, 2002). Themes that encapsulate positive aspects of caring have been identified in a recent review exploring positive perceptions in caring for people with intellectual disabilities (Hastings & Taunt, 2002). Fourteen themes constituting positive perceptions arose from qualitative reviews. These were, pleasure or satisfaction in providing care for the child, perceiving the child as a source of joy and happiness, a sense of accomplishment in having done the best for the child and sharing love with the child. The child was also seen as

providing a challenge or opportunity to learn and develop. Marriages and families were strengthened by caring and a new or increased sense of purpose in life was identified. Caring was also seen as an opportunity to develop new skills, abilities or career opportunities and to become a “better person”. Parental characteristics such as patience and empathy were enhanced and social and community networks were expanded, spirituality was increased, and a changed perspective on life was reported.

The quantitative papers in the review employed a wide variety of measurement tools and concepts to assess positive impact. Positive impact has been conceptualised and assessed as ways of coping and family “hardiness” (Judge, 1998), life satisfaction (Sloper, Knussen, Turner & Cunningham, 1991) and perceived parental competence (Stoneman & Crapps, 1988). Whilst this highlights the wide range of positive gain parents and families may experience from caring, the diversity of measures is testament to the early stage of development of the concept of positive impact.

Positive impact may interact with other carer variables, such as psychological wellbeing. Hastings and Taunt (2002) point out that the effect of positive perceptions on psychological wellbeing has not been addressed sufficiently and there is speculation that a moderating or mediating relationship between gain in the caregiving experience on potential negative affect such as stress and depression may exist (Folkman & Moskowitz, 2000; Hunt, 2003). In the current literature that focuses on poor parental wellbeing in caring, contributory factors to stress and depression include, the syndrome type the child is diagnosed with (Blacher et al., 2005; Ricci & Hodapp, 2003; Griffith, Hastings, Nash & Hill, 2010; Griffith et al., 2011) and challenging behaviours (Blacher & Baker, 2002; Herring et al., 2006; Hassall, Rose & McDonald, 2005; Blacher et al., 2005). There are also

gender differences in reports of stress, with mothers reporting higher levels of stress than fathers (Konstantareas & Homatidis, 1989).

This review seeks to address three aims that are identified in the literature on parental caregiving for people with an intellectual disability. The first section of the review updates from Hastings and Taunt's (2002) review to re-evaluate conceptualisations of positive impact by:

- 1) Identifying themes in qualitative studies that conceptualise positive impact.
- 2) Identifying assessment tools in quantitative studies used to measure positive impact and address the concepts that are measured. Aspects of wellbeing will also be conceptualised by use of measurement tools, in order to address the question in the second part of the review.
- 3) The second section of the review will summarise the relationship between the positive impact of caring and wellbeing and address whether similar influences affect positive impact, including mother and father differences, syndrome type and challenging behaviour.

2. Methodology

2.1. Search Methodology

A systematic literature review was conducted using the databases of PsycInfo ® and Ovid Medline ®. The search criteria are outlined in Table 1.1.

Table 1.1: Search terms employed

Search Term	Variations
Intellectual disability	Learning difficult*; learning disabilit*; intellectual disabilit*; intellectual difficult*; mental retard*; developmental delay; autism (exploded)
Parental	Parental; paternal; maternal; mother; father; parent; carer; family
Positive impact	Positive AND Impact; perceptions; experiences; attributions; gain; benefit; belief; affect

2.2. Exclusion Criteria

The search yielded 228 results. Articles were excluded based on the criteria in Table 1.2.

Articles were not included if they were published before 2002, the date of the last review, if they were not peer reviewed, and if positive impact was a nominal or coincidental area.

Table 1.2: Exclusion criteria applied

Exclusion Criteria	Number of articles eliminated
Removal of duplicates	33
Limit to peer reviewed journals	74
Additional limits of year 2002-2010	26
Related articles but not directly relevant	32
Focus on interventions	15
Focus on support	11
Positive perceptions as a minor part of the paper	6
Not parent carer or a focus on the person with intellectual disability's view	7
Intellectual disability causation focused	6
Animal focused	1
Screening/ Assessment tool focused	1
Editorial	1

A reference search revealed a further nine articles, creating a total of 24 articles included in the review. A table of articles can be found in Appendix 1.

2.3. Quality Review of Articles

A quality review of papers was completed using criteria based on Sale and Brazil's (2004) recommendations, which outlines criteria for qualitative, quantitative and mixed method designed studies. Their criteria have been compiled following a comprehensive literature search of recommended quality assessments. For a quality assessment of quantitative papers, three principles are adhered to which are:

- 1) Truth Value (credibility versus internal validity)
- 2) Applicability (transferability versus external validity/ generalisability)
- 3) Consistency (dependability versus reliability)

There is a fourth principle for qualitative papers and mixed method designs which is

- 4) Neutrality (conformability versus objectivity)

Each of the four criteria has several items that can be rated to assess achievement of a criterion. For this review, six qualitative papers (Appendix 1.2), two mixed method designed papers, (Appendix 1.2 and 1.3) and 16 quantitative papers were assessed using the criteria (Appendix 1.3). Whilst none of the papers fails in fulfilling quality criteria, some papers rank more highly than others. For the qualitative studies, the lowest criteria met is 14 out of a possible 35, and for quantitative studies, the lowest total criteria met is 13 out of a possible 30. The rank order of papers based on the number of criteria met are summarised in Table 1.3. It is worth noting some of the limitations of the individual appraisal criteria.

Some of the items that rate achievement are associated with others, which mean that if one of the criteria is not met, several other criteria are not applicable, thus lowering the

overall score. For example, in criteria outlined for quantitative studies, if a study does not use a control or comparison group then it misses the opportunity to meet three other criteria. Few of the studies in this review used control or comparison groups, primarily because they focused on obtaining data from a preselected source, that being families caring for a child with intellectual disability, and did not necessarily require a comparison to fulfil the study aims. Due to the accessibility of certain groups, potential samples had to be preselected and this meant that none of the studies reached criterion for randomised sampling. Also due to the design of studies in this group, questionnaire data collection, none of the studies met criteria for items related to interventions as these were not carried out and none of the studies met criteria for consistency in the quantitative group, because this refers to a second observer in data collection, which was not needed.

A further criticism of this set of criteria is that statements about ethical approval, confidentiality and consent are required in the papers. Not all of the papers in this review refer to these directly, but it might reasonably be assumed that they have been sought, as all papers in this review are peer reviewed published journal articles.

Despite these limitations, the criteria provide a useful overview of the design and methods that the papers describe. Despite some studies scoring lower than others according to the criteria, all of the papers included in this review have been deemed to contribute to fulfilling the aims of the review.

Table 1.3.: Order or quality of papers used in the review based on Sale and Brazil's (2004)

critical appraisal criteria

Quality order		Truth Value	Applicability	Consistency	Neutrality	Total criteria met
		(max 12)	(max 19)	(max 1)	(max 3)	(max 35)
Qualitative papers	King et al., (2005)	9	14	1	1	25
	Myers et al., (2009)	10	12	1	2	25
	Bostrom et al., (2009)	4	16	0	3	23
	Taunt & Hastings (2002)	4	14	1	2	21
	Corman (2009)	5	13	0	0	18
	Altire & Von Kluge (2009)	6	8	0	0	14
Mixed methods qualitative	Larson (2009)	7	15	0	0	22
	Green (2007)	4	8	0	1	12
		(max 7)	(max 22)	(max 1)	N/A	(max 30)
Mixed methods quantitative	Green (2007)	2	12	0		14
	Larson (2009)	2	12	0		14
Quantitative	Bostrom et al., (2010)	7	17	0		24
	Griffith et al., (2010)	4	17	0		21
	Paczkowski & Baker (2008)	4	16	0		20
	Trute et al., (2007)	3	16	0		19

Quality order (continued)					
	Truth Value (Criteria met)	Applicability (Criteria met)	Consistency (Criteria met)	N/A	Total criteria met
	(max 7)	(max 22)	(max 1)		(max 30)
Olsson & Hwang (2008)	4	15	0		19
Al Yagon & Margalit (2009)	4	15	0		19
Ekas & Whitman (2010)	3	16	0		19
Kayfitz, Gragg & Orr (2010)	5	13	0		18
Greer et al., (2006)	3	14	0		17
Trute et al., (2010)	2	14	0		16
Hastings et al., (2005)	2	14	0		16
Hastings et al., (2002)	1	13	0		14
Mak & Ho (2007)	2	11	0		13
Hastings, Beck & Hill (2005)	1	12	0		13

2.4. Review Structure

The review first defines positive impact and well-being as described in the articles, focusing on emerging themes from qualitative papers and the concepts evident in assessment tools used in quantitative papers. It will also summarise the areas of wellbeing measured in the papers. The review will then examine the relationship between positive impact and parental wellbeing and other factors relating to this, inclusive of mother and father differences, syndrome group, and the role of challenging behaviour affecting perceptions and wellbeing.

3. Defining and Assessing Positive Impact and Wellbeing

3.1. Positive Impact Arising from Qualitative Themes

Eight papers qualitatively assess positive impact in the form of positive perceptions of family carers. These include positive perceptions about the parent, child, family, daily routine and the future, that relate to caring for a child with intellectual disability. Table 2.1. outlines a summary of the main themes and the papers that identify similar themes. Most themes echo those found by Hastings and Taunt (2002), including emotional and spiritual growth, a greater understanding of the world, and a reprioritisation of important values. Other themes that replicate Hastings and Taunt's (2002) findings are extended support from professionals and family members, and parental positive emotions for the child. In addition, there is importance placed on the ability to have hope and a future focus. New themes that have arisen in the literature focus on child development and achievement, viewing the child as unique, an acceptance of diagnosis and source of satisfaction from well-functioning daily routines. Considering the type of themes that recur, they indicate the importance for carers of a personal satisfaction stemming from caring, and a sense of personal reward rather than satisfaction from external and tangible gain.

Table 2.1: Table of positive impact arising from qualitative themes.

Main themes arising from the current review	Themes arising from Hasting & Taunt's (2002) literature review	Studies with similar findings
Hope and knowledge, looking ahead.	Changed one's perspective on life (e.g., clarified what is important in life, more aware of the future).	Altiere & Von Kluge, (2009); King et al., (2005); Taunt & Hastings (2002).
Re-evaluation, reprioritising of beliefs, learning what is important in life.	Changed one's perspective on life (e.g., clarified what is important in life, more aware of the future) Gives a new or increased sense of purpose in life.	King et al., (2005); Myers, Makintosh & Goin Kochel (2009); Taunt & Hastings (2002).
Opportunity to learn.	Has led to the development of new skills, abilities, or new career opportunities Child provides a challenge or opportunity to learn and develop.	Taunt & Hastings (2002).
Growth as a person, including emotional and spiritual growth, gaining courage and strength.	Increased spirituality. Increased personal strength or confidence.	Altiere & Von Kluge (2009); Green (2007) King et al., (2005); Myers et al., (2009); Larson (2009); Taunt & Hastings (2002).

Growth in relation to the outside world, e.g. more understanding of others, stronger values and worldviews.	Become a better person (more compassionate, less selfish, more tolerant).	Green (2007); King et al., (2005); Myers et al., (2009); Larson (2009); Taunt & Hastings (2002).
Pride and joy of child.	Child is a source of joy/happiness.	Green (2007); Corman (2009).
Family benefits, such as support and closeness, stronger marital relationships.	Strengthened family and/or marriage.	Altieri & Von Kluge (2009); Myers et al., (2009); Taunt & Hastings (2002).
Increased support from others.	Expanded social and community networks.	Taunt & Hastings (2002).
Parents positive emotional expressions of the child, including love, affection.	Sense of accomplishment in having done one's best for the child.	Bostrom, Broberg & Hwang (2009).
	Sharing love with the child	
	Pleasure/satisfaction in providing care for the child.	
Good parent child interactions/ relationship.	Sharing love with the child.	Bostrom et al., (2009); Corman (2009).
Acceptance of diagnosis/ disability.	<i>No comparable theme.</i>	Bostrom et al., (2009); Corman (2009); Green (2007); King et al., (2009); Larson (2009).

Uniqueness of child.	<i>No comparable theme.</i>	Corman (2009); Myers et al., (2009).
Well-functioning routines.	<i>No comparable theme.</i>	Bostrom et al., (2009).
Child benefits including traits and attributes, achievements, developmental gains.	<i>No comparable theme.</i>	Altiere & Von Kluge (2009); Bostrom et al., (2009); Corman (2009); Larson (2009); Taunt & Hastings (2002).

3.2. Measures of Positive Impact

Seventeen studies have used measures of positive affect and positive perceptions to gauge positive impact on the parent and family. The most popular measure used is the Positive Contributions Scale of the Kansas Inventory of Parental Perceptions (KIPP, Behr, Murphy & Summers, 1992). This has items that measure learning through experience with special problems, happiness and fulfilment, personal strength and family closeness, understanding life's purposes, personal growth and maturity, awareness of future issues, expanded social network, career or job growth and pride and cooperation.

Despite the focus of the review being on the impact on parents, two measures frequently used, assess the positive and negative impact on the family. These are the Family Impact Questionnaire (FIQ, Donenberg & Baker, 1993) and the Family Impact of Childhood Disability Scale (FICD, Trute & Hiebert-Murphy, 2005) where positive and negative impacts are viewed as separate constructs. The only other measure used that assesses perception, is a five item scale created specifically for a study (Green, 2007). This has items that are similar to the KIPP (Behr et al., 1992) and focuses on experiencing pride and joy of the child, and accomplishment in caring and coping.

The other studies focus on the emotional effect of caring. The Positive and Negative Affect Scale (PANAS, Watson, Clark, & Tellegen, 1988) is the most popular measure assessing emotion, which measures positive and negative emotions on separate scales, as does the Affect Scale (Moos, Cronkite, Billings, & Finney, 1987). There is a further measure used to assess emotional affect which positions positive emotions at an opposing end of a spectrum to depression, which is the Beck Depression Inventory (Beck & Steer,

1996), with three positive alternatives added to each of the 21 items (Chow & Brenton, 2001). The instruments used and the studies that use the measures is shown in Table 2.2.

Table 2.2: Quantitative measures of positive perceptions and affect used by the studies in the literature review

Assessment tools used to measure positive perceptions/ positive affect	Constructs measured by assessment tool	Studies using measure
Kansas Inventory of Parental Perceptions (KIPP, Behr et al., 1992).	The measure has four domains of perception, which are positive contributions of the person with the intellectual disability, social comparisons, causal attributions and mastery and control. The most commonly used domain is the positive contributions scale.	Hastings, Beck & Hill (2005a); Greer, Grey & McClean, (2006); Griffith et al., (2010); Hastings, Allen, McDermott & Still (2002); Hastings et al., (2005b); Kayfitz, Gragg & Orr (2010); Mak & Ho (2007).
The Family Impact Questionnaire (FIQ, Donenberg & Baker, 1993).	Six scales that are rated on a 4-point Likert scale. Items can be summed into negative and positive impact on family.	Blacher & Baker (2007); Blacher & McIntyre (2006); Bostrom, Broberg & Hwang (2010); Olsson & Hwang (2008); Packzowski & Baker (2008).
Family Impact of Childhood Disability Scale (FICD, Trute & Hiebert-Murphy, 2005).	Assesses cognitive appraisals of family consequences of caring for someone with a disability on a 20-item scale. Assess positive and negative as orthogonal scales.	Trute, Benzies, Worthington, Reddon & Moore (2010); Trute, Hiebert- Murphy & Levine (2007).

Maternal perceptions of the benefits of caring for someone with intellectual disabilities.	Measured using five statements, rated on a Likert scale that were developed for this study.	Green (2007).
The Positive and Negative Affect Schedule (PANAS, Watson et al., 1988).	Lists a number of emotions that belong to certain 'dimension scales'. The scales most frequently used in these studies relate to negative and positive affective states.	Ekas & Whitman (2010); Griffith et al., (2010); Hastings et al., (2005a); Trute et al., (2010).
Affect Scale (Moos et al., 1987).	Self-report of perception of affect. Has a positive affect factor and a negative affect factor (including negative affect subscale and global subscale). Items are rated on a 5-point Likert scale.	Al-Yagon & Margalit (2009).
Beck Depression Inventory (Beck & Steer 1996), with three positive alternatives added to each of the 21 items (Chow & Brenton 2001).	A self-report measure where respondents indicate the alternative that best describes how they have been feeling during the last two weeks. Rated on a seven-point likert scale. The positive additions act as the positive affect indicators and are used to assess positive affect.	Olsson & Hwang (2008).

3.3. Defining Psychological Wellbeing

In the literature, poor wellbeing is frequently measured as stress (Parenting Stress Index Short Form, PSI-SF, Abidin, 1995; Questionnaire on Resources and Stress, QRSF, Friedrich, Greenberg, & Crnic, 1983; Ekas & Whitman, 2010; Daily Inventory of Stressful Events, Almeida, Wethington & Chandler, 2002), depression (Center for Epidemiological Studies-Depression scale, CES-D, Radloff, 1977; Beck Depression Inventory, Beck & Steer 1996; Hospital Anxiety and Depression scale, HADS, Zigmond & Snaith 1983) and anxiety (HADS, Zigmond & Snaith, 1983). Measures also assess general wellbeing on the Psychological Well-Being Scale (Ryff & Keyes, 1995) and the Philadelphia Geriatric Center Morale Scale (Lawton, 1972) which measures general mood and morale. Two measures have been used to assess caregiver burden (Burden Assessment Scale, Horwitz & Reinhard, 1995; Reinhard, Gubman, Horwitz & Minsky, 1994; Caregiver Burden Inventory, Novak & Guest 1989), which are based on the premise that the higher the subjective burden, the worse the wellbeing. There are assessments that measure the impact on family organisation, functioning, adaptation and satisfaction as an outcome of wellbeing (Brief Family Assessment Measure III, FAM-BF, Skinner, Steinhauer & Santa-Barbara, 1995; Golombok Rust Inventory of Marital State, Rust, Bennun, Crowe & Golombok, 1990; Family Satisfaction Scale, Olson & Wilson, 1982). Measures of wellbeing therefore assess varied outcomes, inclusive of mental health status, which is assessed with stress, anxiety and depression measures, to more general affective measures. Family wellbeing measuring the functioning of the system is included, as is caregiver burden. This reflects the many types of wellbeing that researchers may feel important when considering caring and also reflects the many areas of wellbeing that care giving may impact upon.

Table 2.3: Wellbeing measures used by studies.

Scale	Area Assessed	Study Using Measure
Parenting Stress Index Short Form (PSI-SF, Abidin, 1990).	Self-report scale using a Likert rating scale that assesses distress and unhappiness in parenting roles. Higher scores reflect higher perceived parenting stress.	Al Yagon & Margalit (2009); Ekas & Whitman (2010); Kayfitz et al., (2010).
Questionnaire on Resources and Stress Short Form (QRSF, Friedrich et al., 1983).	Twenty items assessing impact on parents and family where respondents indicate true or false to an item. The stress score is achieved by summing the number of negatively endorsed items.	Griffith et al., (2010); Hastings et al., (2005a); Hastings et al., (2005b).
Child Related Stress Scale (Ekas & Whitman, 2010).	Eight items scored on a Likert scale. The higher the score the higher degree of stress.	Ekas & Whitman (2010).
Center for Epidemiological Studies-Depression scale (CES-D, Radloff, 1977).	Twenty item self-report of depressive symptoms.	Blacher & Baker (2007); Blacher & McIntyre (2006); Ekas & Whitman (2010).
Beck Depression Inventory (Beck &	A self-report measure where respondents	Olsson & Hwang (2008).

Steer 1996).	indicate on a seven-point Likert scale the alternative that best describes how they have been feeling during the last two weeks.	
Hospital Anxiety and Depression Scale (HADS, Zigmond & Snaith 1983).	A 14-item scale with seven items measuring depression and seven measuring anxiety. Likert scale format to rate items. Used to determine clinical levels of depression and anxiety.	Griffith et al., (2010); Hastings et al., (2005a); Hastings et al., (2005b).
Philadelphia Geriatric Center Morale Scale (Lawton 1972) for general morale/ mood.	A 17 item self-rating scale used to assess general morale/ mood and attitude toward life. 16 items rated on 0 or 1 scale.	Blacher & McIntyre (2006).
The Psychological Well-Being Scale (Ryff, 1989; Ryff & Singer, 2006; Ryff & Keyes, 1995).	42 item scale assessing wellbeing in multiple domains including, personal growth environmental mastery and purpose in life. Items rated on a 5-point subscale. Higher scores reflect higher wellbeing.	Ekas & Whitman (2010); Larson (2009).
Burden Assessment Scale (Horwitz & Reinhard, 1995; Reinhard et al., 1994).	Measures objective and subjective burden, with ratings on items averaged to gain an overall	Green (2007).

	score.	
Chinese version of the Caregiver Burden Inventory (Novak & Guest, 1989).	Negative perceptions are assessed in five areas, emotional burdens, time dependent burdens, developmental burdens, social burdens and physical burnout. Items are rated on a 5-point likert scale with higher scores indicating higher negative perceptions.	Mak & Ho (2007).
Brief Family Assessment Measure III (FAM-BF, Skinner et al., 1995).	14 items measured on a 4-point likert scale to assess family adjustment. A higher score indicates lower family adjustment.	Trute et al., (2010); Trute et al., (2007).
Family Satisfaction Scale to measure family cohesion and adaptability, (Olson & Wilson, 1982).	Measures cohesion and adaptability, 14 items on a 5-point likert scale.	Griffith et al., (2010).
Golombok Rust Inventory of Marital State (Rust et al., 1990).	28 items rated by couples on a 4-point likert scale. Higher scores indicate more dyadic adjustment problems.	Griffith et al., (2010).

3.4. Summary

The conceptualisation of positive impact evident in measures ranges from personal parental traits and emotions to child development and character. The common use of one tool (KIPP, Behr et al., 1992) suggests that there is a shared understanding of what positive impact consists of, although currently there is no widely used definition in the literature. The measures used to define perception (KIPP, Behr et al., 1992 FIQ, Donenberg & Baker, 1993; FICD, Trute & Hiebert-Murphy, 2005) are useful as they measure positive and negative perceptions as separate constructs, rather than positioning positive and negative perceptions at either ends of a continuum, which would imply that they cannot co-exist, (Hastings & Taunt, 2002; Hunt, 2003; Folkman & Moskowitz, 2000). Positive impact in the literature also refers to positive affect, which is a separate construct from perceptions related to caring and pertains to emotionality. The assessment of positive and negative emotions as separate constructs in most of the measures is beneficial (PANAS, Watson et al., 1988; Affect Scale, Moos et al., 1987). However, measures of positive affect may also be deemed to be states of wellbeing and so it is possible that they will overlap with other wellbeing measures that tend to focus on negative affect. There is a wide variety of wellbeing measures in use in the literature, which may make it difficult to form a coherent picture of the relationship between positive impacts and a particular concept of wellbeing.

4. The Relationship between Psychological Wellbeing and Positive Impact

Positive perceptions regarding caring for a child with intellectual disabilities are found even when poor wellbeing is reported, for example in the form of stress (Myers et al., 2009). However, the degree of positive impact differs when poor wellbeing is present. Stress is likely to be accompanied by lower positive perceptions and higher negative perceptions of caregiving. Studies have found that higher parental reports of positive impact are associated with lower parental distress (Kayfitz et al., 2010; Larson, 2009; Al Yagon & Margalit, 2009). High stress is also associated to stronger negative perceptions about care giving (Mak & Ho, 2007) and positive perceptions about caring have been found to be one of the strongest predictors of wellbeing (Olsson & Hwang, 2008).

Positive impact has been found to act as a buffer from stress caused by challenging behaviours (Blacher & Baker, 2007; Paczkowski & Baker, 2008). In addition, parents who hold positive beliefs when their child is young are likely to experience less stress a few years on (Paczowski & Baker, 2008). There is also a different relationship between mothers' and fathers' stress levels and positive perceptions; fathers reporting more positive experiences had partners who reported less parental distress (Kayfitz et al., 2010), intimating that positive perceptions about caring are not just vital for the individual, but also for a well-functioning home.

That a relationship between stress and positive perceptions exists is clear, however it is difficult to describe the nature of the relationship. It is not clear whether lower positive perceptions result directly from the amount of stress, or whether stress would have occurred anyway, but is buffered by positive perceptions, which is the main suggestion arising from the papers. Alternatively, positive perceptions may just not be as high in

individuals encountering more stress, because there are genuinely less things to find positive. The studies have explored other variables that are related to positivity and wellbeing, including coping strategies, self-esteem and sense of coherence and how these may form a triangular relationship with positive impact and wellbeing.

Different coping strategies have been found to be related to positive care giving perceptions in several studies. Active coping strategies and problem coping strategies which are similar in nature, in that they require action to problem solve stressors, have both been found to be related to higher positive impact (Al Yagon & Margalit, 2009; Mak & Ho, 2007). Reframing coping, where the meaning of situation is reappraised, has also been associated to positive perceptions regarding caring (Hastings et al., 2002), whereas emotional coping, where frustrations are expressed emotionally and focus is on reducing heightened emotions have been linked to negative care giving perceptions (Mak & Ho, 2007). These findings imply that parents who hold positive perceptions have better ways of coping. This may help them to feel more effective in the face of challenges, and thus help to reduce stress. Also, having useful ways of coping may create the positive perceptions that parents hold. Findings that positive perceptions and positive affect regarding caring have been linked to a better sense of coherence regarding mastery and understanding of a situation, close family connection (Al Yagon & Margalit 2009), adjustment to disability and heightened self-esteem (Trute et al., 2007), give credence to the idea that better coping strategies influence positive impact. A sense of coherence, self-belief and family support are resources likely to help form better coping mechanisms. All of these characteristics are likely to lower stress, as the individual feels supported, in control and views themselves positively. These characteristics are also likely to contribute to and maintain existing positive perceptions.

The existence of positive impact is without doubt helpful to parents caring for a child with an intellectual disability as wellbeing is increased. This may also broaden capacity for care giving even if the effect of positivity is via a different variable, such as self-esteem, which increases wellbeing. However, other factors may erode positive perceptions and increase stress. These are challenging behaviours and syndrome type, which are discussed later in the review. It is also important to note the earlier acknowledgment of an interrelationship between mother and father positive impact, and look at the differences that may occur in mother and father positive impact.

4.1. Differences in Mothers' and Fathers' Wellbeing and Positive Impact

Studies have found that gender influences the amount of positive impact and the relationship between positivity and wellbeing. Studies that used the KIPP (Behr et al., 1992) found that mothers rated positive perceptions regarding care giving higher than fathers (Hastings et al., 2005a; Kayfitz et al., 2010; Hastings et al., 2005b). Similar subscales in the KIPP were found to be rated highly by mothers. These were; learning through experience of special problems, the child being a source of happiness and fulfilment, a source of strength and family closeness, an awareness about future issues, experience of personal growth and maturity and an expanded social network, career/ job growth (Hastings et al., 2005a; Kayfitz et al., 2010). However, fathers only rated one subscale highly, which was, the child being a source of pride and cooperation (Hastings et al., 2005a).

Although mothers reported more positive perceptions, they also reported higher levels of depression than fathers (Hastings et al., 2005b) and whilst mothers' positive perceptions were not related to fathers' wellbeing, where fathers scored higher on positive perceptions,

their partners reported less distress (Hastings et al., 2005a; Hastings et al., 2005b). Overall, there is a positive correlation between father depression and maternal stress and anxiety. Paternal depression was found to be a significant predictor of maternal stress and maternal depression had an effect on fathers' stress and positive perceptions, (Hastings et al., 2005b).

In contrast to studies that found mothers reported higher levels of positive perceptions about caring, Blacher and Baker, (2007) found that fathers experienced a greater positive impact than mothers did. However, this finding was based on an alternative scale to the KIPP (The Family Impact Questionnaire, FIQ, Donenberg & Baker, 1993). In a longitudinal study, changes in fathers' positive appraisals were seen over time. Mothers reported more positive appraisals regarding family at time one but these converged at time two (Trute et al., 2007). However, this study also used a different scale, the Family Impact of Childhood Disability Scale (FICD, Trute & Hiebert-Murphy, 2005).

Mother-father differences regarding positive impact need to be researched further with comparable scales throughout the literature to draw any firm conclusions. As most studies that compare mother-father differences have used the KIPP, it is worth considering that the KIPP lends itself to positive perceptions that are particularly pertinent to mothers. Alternatively, given that mother and father perceptions may converge over time (Trute et al., 2007), it may be that perceptions were measured at a time when differences were still apparent. There is also the possibility the finding that fathers experienced more positive perceptions than mothers (Blacher & Baker, 2007), was an anomaly compared to the consistency of other studies. The role of mothers and fathers is also worth consideration. Mothers are more likely to be the primary caregiver and therefore may have more opportunity to experience positive impact.

4.2. The Influence of Intellectual Disability and Syndrome Differences on Positive Impact and Wellbeing

Studies suggest that the presence of intellectual disability lowers parental ratings on positive impact scales and heightens ratings on negative impact scales in comparison with parents of a typically developing group of children (Bostrom et al., 2010). Studies are inconsistent as to whether the severity of intellectual disability affects positive and negative impact, with one study finding that the severity of intellectual disability is related to mothers' negative perceptions (Mak & Ho, 2007) and another finding severity of disability to have no impact on positive perception (Blacher & Baker, 2008). Differences in syndrome groups, especially between intellectual disability, autism spectrum disorder and Down syndrome, evidence different effects on positive impact and wellbeing.

The presence of autism spectrum disorder has been found to be related to mothers' negative perceptions (Mak & Ho, 2007; Bostrom et al., 2010) and in comparison to an autism spectrum disorder group, mothers of children with Down syndrome have scored higher on positive contributions scales (Griffith et al., 2010). Mothers and fathers of children with autism spectrum disorder also report more stress than mothers and fathers of children with other intellectual disabilities (Bostrom et al., 2010; Griffith et al., 2010) and parents of children with autism spectrum disorder have reported more negative impact when compared to parents of children with Down syndrome (Bostrom et al., 2010). Studies have suggested various factors as to why children with Down syndrome have less negative impact on parents than other groups. These include increased social competence and sociability (Griffith et al., 2010; Bostrom et al., 2010) less emotionality (Bostrom et al., 2010) and less internalised and externalised behaviour problems (Griffith et al., 2010). Of

the factors that may affect the rating of positive impact, most research has focused on behavioural difficulties.

4.3. Challenging Behaviours and the Influence on Positive Impact and Wellbeing

Studies are consistent in linking child behavioural difficulties to lower parental positive impact and lower parental wellbeing. Behavioural difficulties have been found to predict lower positive impact and higher negative impact for mothers and fathers (Blacher & Baker, 2007; Griffith et al., 2010; Ekas & Whitman, 2010). Behavioural difficulties also increase stress in mothers and fathers (Blacher & Baker, 2007; Griffith et al., 2010; Hastings et al., 2005b; Paczkowski & Baker, 2007; Ekas & Whitman, 2010).

More behavioural problems have been found in children with autism spectrum disorder than in other groups (Blacher & McIntyre, 2006; Griffith et al., 2010; Ekas & Whitman, 2010), including higher levels of aggressive and destructive behaviours, stereotypical and self injurious behaviours. Children with autism spectrum disorder have also been described as showing higher levels of anger, anxiety, depression, low self-esteem, psychosis and withdrawn behaviours (Griffith et al., 2010). These heightened levels of associated difficulties may explain why this group has the most negative impact on perceptions about caring and wellbeing. However other factors that may be particular to this group which effect parental positive impact and wellbeing should not be discounted.

Paczkowski and Baker (2007) have suggested that positive beliefs effect parenting stress via their relationship with children's challenging behaviours. This is the notion that mothers' positive beliefs aid their children in developing higher levels of self-regulation, thus reducing challenging behaviours and therefore reducing stress. Although this is

plausible, the interactive nature of the stress, positive impact and challenging behaviours, has yet to be explored in depth.

5. Discussion

In attempting to define the concept of positive impact, this review may have elicited how many factors are involved in ascertaining how positive impact is derived. There are numerous factors that affect positive impact and therefore it is difficult to give a tight definition of the concept. However it is worthwhile reiterating the statement made in the introduction that positive impact on the parent incorporates positive reflections, emotions and relationships gained from caring for a child with intellectual disabilities. The difficulty in defining the concept is the interaction of variables with one another. A continuum of positive perceptions about the self, family, child and wider social, community and career perceptions, amongst others are pertinent in defining positive impact, but so is a continuum of negative perceptions of the same factors. Then to account for emotions, two continua of ‘positive’ emotion and ‘negative’ emotions must be incorporated. Given the literature, it seems that these continua remain parallel and the position of a parent on one continuum may not be affected by their position on a different continuum. For example, a parent can feel extremely stressed on the ‘negative emotion’ continuum, have high positive perceptions regarding their child’s influence on their life values but have high negative perceptions regarding challenging behaviours experienced. However, there is a complicating issue of other factors acting as extraneous forces on these four continua, which may potentially impact on the position of the parent. Some of these factors have been alluded to by the review, such as coping strategies, sense of mastery and coherence and self-esteem and

others have not been included in this review, such as socioeconomic status, culture and education. How these extraneous factors are involved or how levels of positive impact act as moderators between variables is unanswerable in the context of current literature.

As outlined in the introduction, this review had three aims. The first was to ascertain the themes from the qualitative literature that defined positive perceptions. These were in line with Hastings and Taunt (2002) literature review, with four new themes arising, which were acceptance of diagnosis or disability, uniqueness of child, well-functioning daily routines and child development and achievement. These themes are being explored further in the literature and are becoming more widely recognised.

Acceptance and adjustment seem a fundamental precursor to being able to develop positive perceptions about caring, especially when an initial reaction to a diagnosis may be one of sadness, shock or disbelief (Bostrom et al., 2009; King et al., 2006; Altieri & Von Kluge, 2009) and therefore acceptance in itself is a positive perception. Acceptance and adjustment has also been found to enhance positive impact (MacDonald, Hastings & Fitzsimons, 2010, Trute et al., 2010). The concept in family systems theories of adaptive self-organisation seems essential to coming to terms with a diagnosis of disability. However, as the model alludes, adjustment can create other weaknesses in the family system, so where the family has successfully adapted to this stressor, weaknesses such as marital strain or poorer wellbeing may well become apparent.

A further new perception held was celebrating the uniqueness of the child. This may be a new perception because of further societal awareness of people with intellectual disabilities and a drive over the last few years to focus on community integration as opposed to segregation of people with disabilities (DoH, 2009). A reduction in stigma and a more open society regarding individual difference may make it easier for parents to

celebrate the uniqueness of their child and the different achievements that a child with a disability may attain. The new theme of 'well-functioning routines' is something that may have been overlooked previously because it seems such a practical construct. However, research has found that the smaller daily experiences and needs of parents, such as working patterns and leisure time can contribute to stress which can accumulate over time (Smith et al., 2010) and so it is feasible that well-functioning routines are important for positive impact and stress reduction. This possibility may depend on successful adaptation of family functioning, where routines of all the family members have changed to accommodate the person with the intellectual disability.

The second aim of this review was to examine the quantitative measures that have been employed in the research. The measures used to assess positive perceptions were consistent throughout the literature with the primary measures being the KIPP (Behr et al., 1992), FIQ (Donenberg & Baker, 1993) and FICD (Trute & Hiebert-Murphy, 2005). Measures that focus on emotional affect are also consistent throughout the literature with the primary assessment being the PANAS (Watson et al., 1988). It is promising that so few tools have been used, as it indicates an emerging shared understanding of positive impact. However, as yet there is no widely used working definition for positive impact and it would be helpful to differentiate positive perception from positive affect. There is also no model that accounts for positivity, which would be useful for future research into positive impact.

Thirdly, the relationship between wellbeing and positive impact was explored. There was a common relationship between stress and positive impact although the nature of this relationship is, yet, unclear, especially when other variables were included, such as coping strategies, sense of coherence and self-esteem. Despite this, positive perceptions pertaining

to caring appear to enhance wellbeing and make the role of care giving less stressful, perhaps further enhancing capacity to engage in caring (Larson, 2009).

From this review there is an indication of differences in mother- father positive impact, however it is not clear whether these differences are due to the assessment measures used or other factors such as care giving roles. In their review, Cox and Paley (1997) found that roles of mothers and fathers within family systems became more set apart as ‘worker’ and ‘parent’ when a child was born and that this caused conflict between the couple. When a child has a disability, these roles may be intensified and alongside other potential stressors such as lack of time and sleep, marital relationships may be further strained. When looking at it from this perspective it seems unsurprising that mothers’ and fathers’ perceptions or state of wellbeing can affect one another. This raises a question of whether child intellectual disability influences this dynamic more or equally to parenting typically developing children. Further research is needed to clarify this.

Challenging behaviour primarily found in autism spectrum disorder groups was the most common variable that influenced positive perceptions. This relationship seems intuitively understandable considering that challenging behaviours are a common factor reportedly effecting mental health of caregivers of people with intellectual disabilities (Blacher & Baker, 2002; Herring et al., 2006; Hassall et al., 2005; Blacher et al., 2005). In line with family systems theory, if a family is experiencing continuing stressors to the system, such as repeated challenging behaviours, the family may be adaptively reorganising repetitively, thus never giving time for a new pattern of functioning to emerge, leaving the family in a continued cycle of organisation without time to consolidate change.

As the literature stands, positive impact can be defined as positive emotional affect and/ or positive perceptions pertaining to self, child, family and wider social involvement

resulting from caring for a child with an intellectual disability. Whilst preliminary findings indicate that positive perceptions act as a buffer against poor wellbeing, further research needs to disentangle the relationship between, stress, positive perceptions, challenging behaviours and other variables.

5.1. Limitations of Review

There are several limitations to this review. The papers incorporated in this review included qualitative, quantitative and mixed method approaches of differing quality, which means that the studies are not directly comparable. However, the qualitative papers have been used solely to draw out themes of positive impact in the first part of the review, which makes the other papers more homogenous.

Papers were selected for the review that directly referred to positive impact or some variation thereof. This meant that other variables that could be viewed as positive, which may have been valuable to the review, were not included. These were constructs such as perceptions regarding child temperament (Ricci & Hodapp, 2003), adjustment (Lloyd & Hastings, 2008), hope (Lloyd & Hastings, 2009a), locus of control (Lloyd & Hastings, 2009b) and acceptance (MacDonald et al., 2010). Some of these factors have emerged as themes in the qualitative review and therefore it would be helpful to explore these further. In addition, there are extraneous variables that have not been explored in this review, but that may be useful in understanding positive impact, which are the role of parental socioeconomic position and culture (Blacher & Baker, 2007; Blacher & McIntyre, 2006). These have also been noted by Kai-sang Yau and Li-Tsang (1999) to help families adapt and adjust to a diagnosis of intellectual disability.

5.2. Clinical Implications

These findings indicate that parental caregivers of children with an intellectual disability do report positive perceptions about caring for their child and experience positive emotions, even whilst they may be experiencing stress, depression and report negative perceptions. As positive impact may buffer the effect of stress and enhance personal wellbeing by being associated to factors such as higher self-esteem and sense of coherence, it makes sense for professionals to identify with carers the positive impact of caring when helping with the negative impact. By attempting to raise positive impact or associated positive wellbeing factors, the general coping strategies and capacity to care may increase in parents. It may help clinicians to explore the positives that parents hold particularly important and focus on strengthening these positive aspects. However, it should be remembered that having positive perceptions about an event, person or situation is not necessarily a precursor to psychological wellbeing and that primary sources of stress, such as challenging behaviours may need to be addressed simultaneously for a comprehensive package of care. In addition, it needs to be noted that not all parents may hold positive perceptions and that pressing parents for a positive view may result in answers due to pressures of social desirability and guilt.

5.3. Future Directions

The role of positive emotions and perceptions in helping with carer wellbeing needs to be clarified within the literature, which would help to form a working definition of positive impact and lay the foundations of working models of positive perceptions. The relationship of secondary variables associated to positive impact needs further exploration and would also be helpful in discerning how a model of positivity might work in trying to help parental carers. In addition, it would be useful to further examine the relationship between stress, positivity and challenging behaviour as the findings may be especially pertinent in a clinical setting.

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EMPIRICAL PAPER

Autism Spectrum Disorder, Challenging Behaviours and Maternal Stress

Abstract

Aims: Autism spectrum disorder and challenging behaviour are associated with parental stress. However, few studies have examined the relationship between stress and challenging behaviour and the person characteristics that are associated with challenging behaviour. This study aims to explore the relationship between these variables in order to elucidate the predictors of stress.

Method: Fifty-one participants aged between 6-49 years and their mothers participated. Questionnaires determined autistic characteristics, presence of challenging behaviours and parental stress. Two groups of participants with autism spectrum disorder, defined by the presence and absence of challenging behaviour are compared.

Results: In the challenging behaviour group, pleasure and interest, reciprocal social interaction and adaptive behaviour are lower in comparison to the no challenging behaviour group. Levels of impulsivity are higher in the challenging behaviour group. There is a significant difference of age between groups. Correlations of person characteristics and stress, show pleasure and interest, adaptive functioning and reciprocal social interaction to be negatively correlated to parental stress, and impulsivity to be positively related to parental stress. A binary logistic regression analysis found impulsivity to be the only predictor variable of parental stress.

Conclusions: Autistic characteristics are more severe when there is a presence of challenging behaviours. These characteristics are also related to parental stress. These

results support other findings, with impulsivity amongst other autistic characteristics as an emerging theme in the literature that needs further exploration.

1. Introduction

Psychological distress associated with raising a child with an intellectual disability is well documented, with parents reporting higher levels of stress and depression than parents of typically developing children (Blacher & Baker, 2002; Singer & Floyd, 2006; Blacher, Neece & Packowski, 2005; Hatton & Emerson, 2003; Qin, Tang, Zhu, Liang, & Zou, 2009; Bauminger, Solomon & Rogers, 2010; Ingersoll & Hambrick, 2011). A number of practical issues such as housing, respite, work and financial difficulties are identified as contributory to stress (Davys & Haigh, 2007; Gilbert, Lankshear & Petersen, 2008; Wodehouse & McGill, 2009). Social limitations are also related to poor wellbeing, including isolation, family and social conflict and a restricted lifestyle (Todd & Shearn, 1996; Johnson, O'Reilly & Vostanis, 2006; Dyson, 2010). Other factors that influence stress include a lack of support and available information (Rogers, 2007; Kenny & McGilloway, 2007; Davys & Haigh, 2007; Tehee, Honan & Hevey, 2009; Qin et al., 2009) and demands on time (Sawyer et al., 2010). Two person characteristics that are consistently related to parental stress are the presence of autism spectrum disorder and challenging behaviour (Estes et al., 2009; Bostrom, Broberg & Hwang, 2010; Griffith, Hastings, Nash & Hill, 2010; Griffith et al., 2011).

Challenging behaviours are more prevalent in autism spectrum disorder than in other types of intellectual disability (McClintock, Hall & Oliver, 2003; Blacher & McIntyre, 2006; Griffith et al., 2010; Ekas & Whitman, 2010; Matson, Wilkins & Macken, 2009a). Aggression, disruptive behaviour and self-injury, are significantly more prevalent among those with autism spectrum disorder (McClintock et al., 2003; Baghdadli, Pascal, Grisi & Aussilloux, 2003; Murphy, Healey & Leader, 2009; Griffith et al., 2010; Matson, Mahan,

Hess, Fodstad & Neal, 2010) and the prevalence of these behaviours is higher when there is lower IQ and stereotyped behaviours are evident (McTiernan, Leader, Healy & Mannion, 2011). Challenging behaviours have been found to be associated to high levels of parental distress in numerous studies (Blacher & Baker, 2007; Griffith et al., 2010; Hastings et al., 2005a; Packowski & Baker, 2007; Ekas & Whitman, 2010; Herring et al., 2006; Donenberg & Baker, 1993; Hastings, 2002; Hastings, 2003). It is clear therefore that there is likely to be a complex relationship between challenging behaviour, autism spectrum disorder and stress in parents.

The relationship between these variables is further complicated by differences in the presentation in autism spectrum disorder. Autism spectrum disorder is typically defined by social and communication deficits and the presence of restricted, repetitive behaviours (American Psychiatric Association, 2000; Shattuck et al., 2007). These features are more prominent in people with autism spectrum disorder when challenging behaviours are present (Shattuck et al., 2007; Murphy et al., 2009). High levels of impulsivity are also evident in people with autism spectrum disorder (Aman, 2004; Bradley & Isaacs, 2006). Impulsivity and overactivity have also been found to be heightened in groups of people with varying intellectual disabilities showing challenging behaviours (Arron, Oliver, Moss, Berg & Burbidge, 2011; Sloneem, Oliver, Udwin & Woodcock, 2011) and in genetic syndrome groups (Oliver, Berg, Burbidge, Arron & Moss, 2010). Individuals with autism spectrum disorder have also been described as having higher levels of anger, anxiety, depression, low self-esteem, and withdrawn behaviours (Hartley, Sikora & McCoy, 2008; Griffith et al., 2010). Any of these characteristics may also be related to higher levels of stress in parents.

The level of ‘severity’ of autism has been found to be a strong, consistent predictor of stress in parents (Lyons, Leon, Phelps & Dunleavy, 2010) and it is the severity of autism

that has also been found to predict increased behaviours associated with autism spectrum disorder. These include stereotypy and self-injury (McClintock et al., 2003), challenging behaviours (Matson et al., 2009a) and lower adaptive functioning (Liss et al., 2001). Research has only recently started to focus on autistic characteristics that relate to parental wellbeing in addition to challenging behaviour.

Studies researching autism spectrum disorder and parental stress specifically have identified a variety of characteristics that relate to poor parental wellbeing. These are reduced sociability and communication (incorporating lack of eye contact and echolalia; Ingersoll & Hambrick, 2011), lack of speech (Liwag 1989; Ekas & Whitman, 2010), low social relatedness (Davis & Carter, 2008; Ekas & Whitman 2010; Griffith et al., 2010) and parent child relationship problems (Davis & Carter, 2008). In autistic spectrum groups, characteristics that affect parental wellbeing that are related to impulsivity and emotional instability, include hyperactivity (Liwag, 1989; Ingersoll & Hambrick, 2011), regulatory problems (Davis & Carter, 2008; Ekas & Whitman, 2010) and negative emotional behaviours (Griffith et al., 2010; Ekas & Whitman, 2010). Externalising behaviours related to parental psychological distress are aggression (Liwag, 1989; Davis & Carter, 2008; Ekas & Whitman, 2010; Griffith et al., 2010, Ingersoll & Hambrick, 2011), destructiveness (Griffith et al., 2010; Ingersoll & Hambrick, 2011) and self-injurious behaviours (Konstantareas & Homatidis, 1989; Griffith et al., 2010; Ingersoll & Hambrick, 2011). The interaction of these variables is outlined in Figure 1.1.

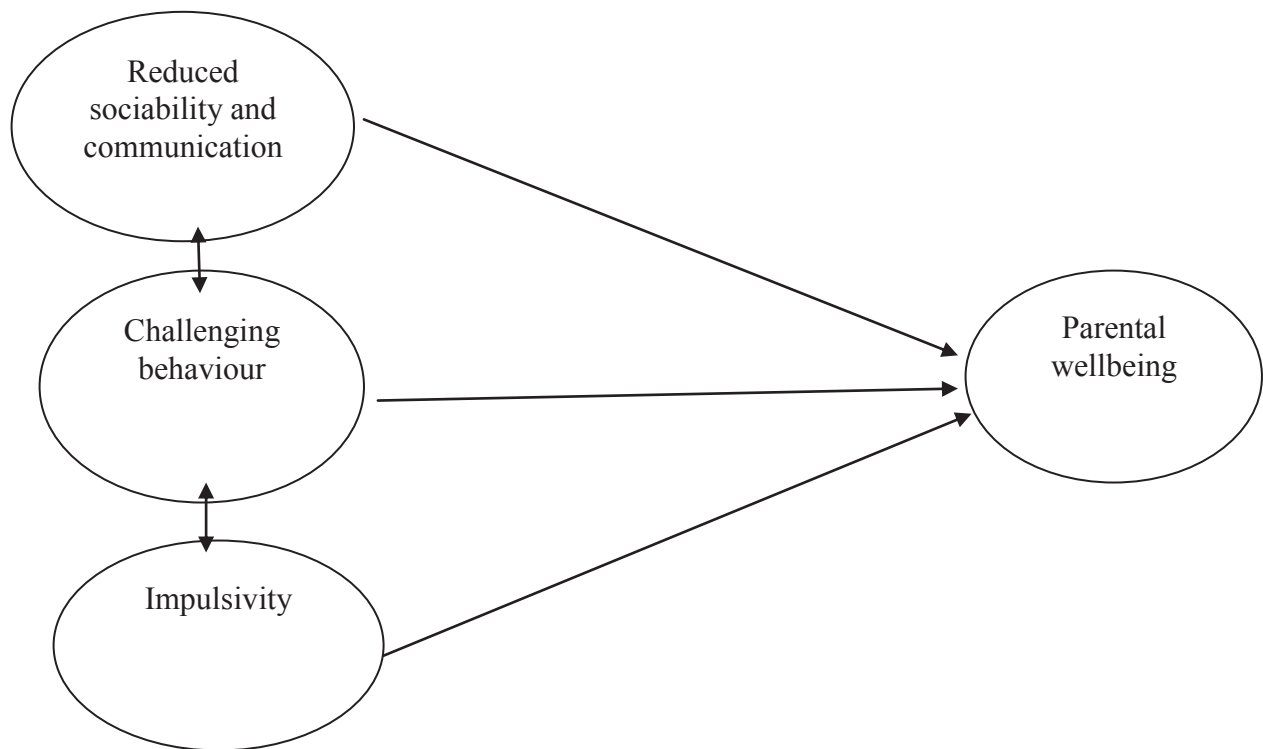


Figure 1.1: Model of participant characteristics and their relationship to parental wellbeing

In comparison to research focusing on parental stress and autistic characteristics, research focusing on parental depression is limited. However, studies that have measured parental depression have found that it is higher in parents of children with autism spectrum disorder than in parents of typically developing children (Mickeviciene, Sinkariova & Perminas, 2009). The severity of autistic characteristics is associated to parental depression as are challenging behaviours in people with autism spectrum disorder (Ekas & Whitman, 2010; Ingersoll & Hambrick, 2011; Meltzer, 2011). Barker et al. (2011) showed that in periods during which people with autism spectrum disorder show higher challenging behaviours, depression in parents is also raised. Overall, the frequency, severity and diversity of autistic characteristics have all been associated to maternal negative socio-emotional functioning (Ekas & Whitman, 2010).

Given the findings of these studies it follows that as some person characteristics are associated with challenging behaviour (e.g. stereotypical behaviours, Shattuck et al., 2007; Murphy et al., 2009 and impulsivity, Arron et al., 2011; Sloneem et al., 2011), it is possible that stress in parents of people with autism spectrum disorder who show challenging behaviour, might be related to these characteristics as well as challenging behaviour. It is important therefore to assess the features of autism spectrum disorder in addition to the challenging behaviour when trying to predict stress in parents.

Ekas and Whitman (2010) note that research into the relationship between autism spectrum disorder and parental wellbeing have used measures that broadly assess autism symptoms, including the Childhood Autism Rating Scale (CARS, Schopler, Reichler, DeVellis & Daly, 1980) and the Autism Severity Index (ASI, Benson, 2006) in relation to parental stress. Other broad measures used to assess autistic symptom severity include the Autism Behavior Checklist (Krug, Arick, & Almond, 1980) which consists of 57 items describing specific symptoms associated with autism and general behaviour issues identified in people with autism (used in Ingersoll & Hambrick, 2011). Matson et al. (2009a) also used a general autism checklist, the Autism Spectrum Disorders-Behaviour Problems for Children (ASD-BPC, Matson, González, Wilkins & Rivet, 2007; Matson et al., 2009a), which focuses on disruptive, aggressive and stereotypical behaviours. This study uses the Social Communication Questionnaire, which is a valid tool to identify autism spectrum disorder (Chandler et al., 2007) and widely used.

This study aims to extend the literature by investigating the relationship between previously identified child characteristics associated with challenging behaviour and the relationship between these characteristics, challenging behaviour and parental stress. The study includes participants that reach a cut off score for Autism Spectrum Disorder on the

Social Communication Questionnaire, a screening measure for autism and autism spectrum disorder (Rutter, Bailey & Lord, 2003). Given the background literature, the study has two aims:

- 1) To explore the relationship between challenging behaviour and person characteristics associated with challenging behaviour and maternal stress. It is hypothesised that when challenging behaviours are present autistic characteristics such as adaptive functioning, reciprocal social communication, communication, mood, pleasure and interest will be lower, whereas impulsivity, overactivity and repetitive behaviours will be evident at higher levels.
- 2) To explore the relationship between challenging behaviour, person characteristics and parental stress.

2. Method

2.1. Recruitment of Participants

Participants were parents, their children and adult children with autism spectrum disorder. Participants had previously participated in an ongoing, large scale study which investigates the relationship between challenging behaviours and person characteristics in children and adults with genetic disorders and autism spectrum disorder (Oliver et al., 2010; Arron et al., 2011; Moss, Oliver, Arron, Burbidge, & Berg, 2009). Participants in the autism spectrum

group were contacted through the National Autistic Society via their membership in London and Birmingham. Participants responded directly once they had decided to participate and were asked if they agreed for their details to be held for further research. Those participants that did agree for follow up contact to take place were contacted directly and asked to participate in this study.

2.2. Procedure

After receiving ethical approval for the study (Appendix 2), participants were sent a covering letter and information sheet explaining the aims of the study (Appendix 3), an informed consent form (Appendix 4) and a pack of questionnaires (Appendix 5). A stamped addressed envelope was provided for the return of the questionnaires. In return for their participation in the study, parents received a summarised report of the questionnaire scores and interpretation of this for their own use and to share with other professionals.

2.3. Participant Information

Of the 284 participants contacted, 101 returned the questionnaires (35.56% response rate). Of these, participants were excluded if they did not reach the cut off score (15) for autism spectrum disorder on the Social Communication Questionnaire (n=24, 23.8%; SCQ, Rutter et al., 2003), or if they had not completed enough items on individual questionnaires to derive an overall score (n=12, 11.8%). Participants who did not reside with parents were also excluded (n=11, 10.8%). Three fathers were excluded from the analysis, as studies have found differing perceptions and levels of stress and depression in fathers and mothers

(Hastings, Beck & Hill, 2005b; Hastings et al., 2005a; Tehee et al., 2009; Kayfitz, Gragg & Orr, 2010) and the father sample was not large enough to use for comparison to the mothers. The final sample number was 51.

2.4. Parental Information.

Parental characteristics were derived from a demographic questionnaire (see Table 1.1). Information on mothers and fathers was gathered from the demographic questionnaire, but mothers completed all of the questionnaires. The average age of mothers was 46.8 years (range, 35-85, SD= 6.8) and of fathers 49.15 years (range, 37-85, SD=9.01). Most mothers were married or living with a partner, 78.4% (n=40) and 21.6% (n=11) lived alone. Parents' educational status was at the higher end of the educational spectrum, many mothers and fathers had a University degree or higher, (n=27, 52.9%; n=22, 56.4%) respectively. Family income was also at the higher end of the spectrum with 56.9% of families earning a joint income of £35,000 per annum upwards, and 21.6% (n=11) of families earned equal to or above £65,000.

Table 1.1: Means, ranges, standard deviations and percentages of demographic information depicting parental characteristics.

		Mother	Partner
Age	Mean(SD)	46.8 (6.8)	49.15 (9.01)
	Range	35-85	37-85
Relationship status	Married, living with spouse	37 (72.5%)	
	Living with partner	3 (5.9%)	
N (%)	Divorced/Separated/ Widowed		
	/ Single, living alone	11(21.6%)	
Educational Status	No formal qualifications	2 (3.9%)	1 (2.6%)
	<5 GCSE (grade A-C) or equivalent	2 (3.9%)	3 (7.7%)
	>5 GCSE (grade A-C) or equivalent	13 (25.6%)	6 (15.4%)
	>3 A-Levels or equivalent	7 (13.7%)	7 (17.9%)
	University degree or equivalent	20 (39.2%)	14 (35.9%)
	Masters/ Doctorate or equivalent	7 (13.7%)	8 (20.5%)
Total annual income	< than £15,000	5 (9.8%)	
	£15,001 to £25,000	7(13.7%)	
	£25,001 to £35,000	10 (19.6%)	
	£35,001 to £45,000	5 (9.8%)	
	£45,001 to £55,000	7 (13.7%)	
	£55,001 to £65,000	6 (11.8%)	
	> £65,000	11(21.6%)	

2.5. Information about Participants with Autism Spectrum Disorder.

The participants with autism spectrum disorder ranged in age from 6-49 years ($M=14.27$, $SD= 6.85$) and, as expected, the majority of participants were male ($n=44$, 86.3%). All participants were mobile and most were verbal ($n=44$, 86.3%). All participants scored above the cut off for autism spectrum disorder on the Social Communication Questionnaire (15), with 20 individuals (39.2%) scoring between 15 and 21, the lower scoring range to determine the presence of autistic spectrum disorder, and 31 (60.8%) scored at the higher end of the scoring range (22 and above), indicating the likely presence of autism. The mean score of the SCQ was 22.7 ($SD=5.17$). The average score on the self help subscale of the Wessex Scale (Kushlick, Blunden & Cox, 1973) which gives a measure of adaptive functioning was 7.37 ($SD=1.5$), indicating a reasonable level of adaptive functioning.

2.6. Measures

A battery of measures was received by parents. Only the measures used in this study are presented. A demographic questionnaire was used to capture generic information.

Assessments that depicted child characteristics were: a measure of adaptive functioning (Wessex Scale, Kushlick et al., 1973), a measure of autism spectrum disorder (Social Communication Questionnaire, SCQ, Rutter et al., 2003), a measure of repetitive, restrictive and stereotyped behaviours (The Repetitive Behaviour Questionnaire, RBQ, Moss & Oliver, 2008), a measure of hyperactivity and impulsivity (Activity Questionnaire, AQ, Burbidge & Oliver, 2008), a measure of mood and pleasure (Mood, Interest and Pleasure Questionnaire, MIPQ, Ross & Oliver, 2003; Ross, Oliver, & Arron, 2008) and a

measure of challenging behaviour (The Challenging Behaviour Questionnaire, CBQ, Hyman, Oliver & Hall, 2002). Parental measures used were a measure of stress (The Questionnaire on Resources and Stress, QRS-F, Friedrich, Greenburg, & Crnic, 1983) and of depression (The Hospital Anxiety and Depression Scale, HADS, Zigmond & Snaith, 1983; Snaith & Zigmond, 1994).

Demographic Questionnaire.

The demographic questionnaire provides information about the child including age, gender, mobility and verbal ability. It also gathers parents and carers information, including their relationship to the child, gender, age, educational status and family income.

Wessex Scale (Kushlick, Blunden & Cox, 1973).

The Wessex Scale (Kushlick et al., 1973) is a carer report comprising two subscales. The Social and Physical Incapacity scale and Self Help and Literacy Scale which assess continence, walking, self-care, vision, hearing, speech and literacy. The scale has good inter-rater reliability when assessing children and adults (Kushlick et al., 1973; Palmer & Jenkins, 1982).

Social Communication Questionnaire (Rutter, Bailey & Lord, 2003).

The Social Communication Questionnaire (SCQ) was formerly the Autism Screening Questionnaire (Berument, Rutter, Lord, Pickles & Bailey, 1999). It assesses social and communication skills in people thought to have autism, aged 4 and over. It is a carer report

consisting of the subscales communication, reciprocal social interaction and restricted, repetitive and stereotyped behaviours. Higher scores indicate more atypical behaviours and the scale differentiates between those with an Autistic Spectrum Disorder (scores of 15 and over) and those with Autism (scores of 22 and above). The tool has been identified as valid and useful in identifying autism in children (Eaves, Wingert & Mickelson, 2006; Chandler et al., 2007). It also has good concurrent validity with the Autism Diagnostic Interview and the Autism Diagnostic Observation Schedule (Berument et al., 1999; Howlin & Karpf, 2004). The sensitivity of the SCQ has been found to increase with child age (Charman et al., 2007), and has been found useful to identify features of autism in other syndromes (Howlin & Karpf, 2004).

The Repetitive Behaviour Questionnaire (Moss & Oliver, 2008).

The Repetitive Behaviour Questionnaire (RBQ, Moss & Oliver, 2008) is an informant report for use for people with an intellectual disability. It consists of 19 items relating to specific types of repetitive behaviour. The five subscales are grouped into stereotyped behaviour, compulsive behaviour, insistence on sameness, restricted preferences and repetitive use of language. Items are based on a 5 point Likert scale and are rated over the last month.

The questionnaire has strong inter-rater reliability, high test–retest reliability, and strong concurrent validity with measures such as the Autism Screening Questionnaire (Moss & Oliver, 2008). It has good psychometric properties, with inter-rater reliability for items ranging from 0.46 to 0.80, with 73% of items above 0.80; test-retest reliability coefficients range from 0.61 to 0.93 at item level (Moss & Oliver, 2008; Moss et al., 2009).

Activity Questionnaire (Burbidge & Oliver, 2008).

This is a carer based questionnaire that assesses hyperactivity and impulsivity in individuals with an intellectual disability. It consists of three subscales, overactivity, impulsivity and impulsive speech. Items are scored on a 5-point Likert scale with responses ranging from never to always. Item level inter-rater reliability range from 0.31 to 0.75 (mean 0.56) and test–retest reliability ranges from 0.60 to 0.90 (mean 0.75) (Burbidge et al., 2010). Correlations for inter-rater and test retest reliability are at 0.70 or above at the subscale and full-scale level, indicating that this is substantial (Burbidge et al., 2010). Internal consistency is good, and the subscales have been found to be separate from adaptive ability, meaning that the questionnaire can be used with individuals with a wide range of disabilities (Burbidge et al., 2010).

Mood, Interest and Pleasure Questionnaire (Ross & Oliver, 2003; Ross, Oliver & Arron, 2008).

The Mood, Interest and Pleasure Questionnaire have two subscales, mood, and interest and pleasure. The questionnaire is a carer report, based on observation in the previous two-week period. The questionnaire has good test–retest reliability (0.87) and good inter-rater reliability coefficients (0.94) alongside good internal consistency, (0.94) (Ross & Oliver, 2003). Evidence to support the construct validity was obtained by correlating scores with the Lethargy and Social Withdrawal scale on the Aberrant Behavior Checklist (Aman & Singh, 1986). A revised version of the questionnaire (Ross et al., 2008) has also been found to have good psychometric properties, with good internal consistency (Cronbach's alpha

coefficients: total=0.88, Mood= 0.79, Interest and Pleasure= 0.87), test-retest (0.97) and inter-rater reliability (0.85), (Ross et al., 2008).

The Challenging Behaviour Questionnaire (Hyman, Oliver & Hall, 2002).

The Challenging Behaviour Questionnaire (CBQ, Hyman et al., 2002) is an informant based questionnaire evaluating whether there is presence of self-injury, physical aggression, verbal aggression, destruction of property and inappropriate vocalisations in the last month. The questionnaire has been shown to have good inter-rater reliability with reliability coefficients range from 0.61 to 0.89 (Hyman et al., 2002). The measure examines eight presentations of self-injurious behaviour (Bodfish et al., 1995). In the current study the questionnaire was used to establish the presence or absence of challenging behaviour, grouping challenging behaviours of self injury, aggression and property destruction.

The Questionnaire on Resources and Stress (QRS-F, Friedrich, Greenburg, & Crnic, 1983).

A shortened version of The Parent and Family problems subscale from the Questionnaire on Resources and Stress – short form (QRS-F, Friedrich et al., 1983) was used to measure parental stress and perceived resources. This was a seven item questionnaire (based on Griffith, 2011) where five items were removed from the original subscale to avoid overlap in measures, as they have been identified as measuring depression rather than parental stress (Glidden & Floyd, 1997). The items were reduced to seven by selecting items with the highest total correlations. A strong correlation was found between the full 15 item scale

and 7 item scale ($r=0.75$, $p<0.05$.) and reliability was good (Kuder-Richardson co-efficient =0.82) (Griffith et al., 2011). Parents circle true or false in relation to statements such as ‘caring for X puts a strain on me’. Specific investigation into the QRS-F in association with autism, has found good reliability, expected associations with social support, and relationships between coping and autism severity (Honey, Hastings & McConachie, 2005).

The Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983; Snaith & Zigmond, 1994).

The depression subscale of the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983; Snaith & Zigmond, 1994) was used to measure levels of depression in parents. As a single scale this consists of seven items which are rated on a 0-4 point Likert scale. Items such as “I feel as though I am slowed down” assess depression. It omits physical symptoms to avoid mistaking anxiety or depression for underlying medical disorders. The HADS has been found to be valid in identifying anxiety and depression and their severity (Bjelland, Dahl, Haug & Neckelmann, 2002; Herrmann, 1997) and research in different populations has suggested that there is good agreement with other measures such as the Center for Epidemiological Studies Depression scale (Katz, Kopek, Waldron, Devin, & Tomlinson, 2004). The HADS has been widely used in community samples of parents of children with intellectual disabilities and has excellent psychometric properties (Hastings et al., 2005b). The anxiety component of the scale was omitted from the questionnaires as ongoing research has indicated that the anxiety scale is oversensitive in this population (C. Oliver, Personal Communication, 6th September, 2010) and given the background literature, depression is an area warranting attention.

2.7. Data Analysis

To determine the presence of challenging behaviour three questions from the CBQ were used. The questions determined whether self-injurious behaviours, aggressive behaviours and property destruction had occurred in the last month. The participants showing any of the challenging behaviours formed the challenging behaviour group.

All scores for measures were subject to Kolmogorov-Smirnov tests in order to ascertain normal distribution. The QRSF was the only measure not normally distributed and the data could not be transformed successfully. Therefore, the QRSF was subjected to non-parametric analyses.

Descriptive statistics including means, standard deviations, ranges and frequencies were calculated for child and mother variables. T-tests were completed to assess the difference of child characteristics between challenging and no challenging behaviours groups. The eta values for each significant variable were also calculated to identify the effect size.

In order to explore whether participant characteristics are related parental stress, Spearman's Rho correlations were conducted between the variables found to be raised with the presence of challenging behaviour and parental stress.

A binary logistic regression was completed to explore whether autistic characteristics are predictive of parental stress. The stress measure, the QRSF, is a continuous variable, and was recoded into 'high stress' and 'low stress' categories using the median split. The 'high stress' group had scores on the QRSF of six upwards, this consisted of 28 participants (54.9%). The participants in the 'low stress' group had scores of five or

below on the QRSF. There were 23 participants (45.1%) in this group. The data was checked for outliers and multicollinearity amongst the predictor variables. No outliers or high correlation between the variables were found. The binary logistic regression was completed with the dependent variable of stress and predictor variables of: challenging behaviour (defined by the two groups), adaptive functioning (Wessex), pleasure and interest (MIPQ), reciprocal social interaction (SCQ) and impulsivity (AQ).

3. Results

3.1. Challenging Behaviour

Approximately half of the participants had shown some form of challenging behaviours in the last month, 51.9% (n=27) had shown self-injurious behaviours, 48.1% (n=25) had shown physical aggression and 48.1 % (n=25) had destroyed property. The total number of participants showing at least one form of challenging behaviours was 37 (72.5%). The total number showing no challenging behaviours was 14, (27.5%). Participants tended to show more than one type of challenging behaviour and the groups of combined types of challenging behaviours were too small to act as independent groups. Seven participants showed a combination of aggression and property destruction, four showed aggression and self-injury and four property destruction and self-injury. Three participants showed aggression only, three showed property destruction only and four self-injurious behaviours only. A third of participants showing challenging behaviours exhibited all three types of challenging behaviours (n=12, 32.4%).

3.2. Characteristics of Participants in the Challenging Behaviour and No Challenging Behaviour Groups.

In order to explore the relationship between person characteristics and challenging behaviours, participants were allocated to groups, those showing at least one form of challenging behaviour (CB group) and those showing no challenging behaviour (NCB). The first hypothesis was that person characteristics will differ between the group that shows challenging behaviours and the group who does not. Table 2.1 shows the descriptive statistics, means, standard deviations, frequencies and results of statistical analyses.

Participants in the no challenging behaviour group ranged in age from 9-49 years ($M=18.92$) and in the challenging behaviour group 6-22 years ($M=12.51$). Most participants in both groups were male (NCB, 78.6%, $n=11$; CB, 89.2%, $n=33$). All participants were mobile and most were verbal (NCB, 92.9%, $n=13$; CB, 83.8%, $n=6$).

Independent t-tests indicated that age, adaptive functioning, reciprocal interaction, pleasure and interest and impulsivity differed significantly between groups (see Table 2.1). The effect size of adaptive functioning was large ($\eta^2 = 0.21$; 21%) as was pleasure and interest ($\eta^2 = 0.1$; 10%). Age had a moderate effect ($\eta^2 = 0.09$; 9%) alongside reciprocal interaction ($\eta^2 = 0.08$; 8%) and impulsivity ($\eta^2 = 0.08$; 8%). As expected, the presentation of a number of person characteristics previously associated with challenging behaviour was more prominent in the group showing challenging behaviour and parental stress was significantly higher in this group.

Table 2.1: Means, standard deviations (SD) and T-tests/ Mann Whitney-U tests among autism characteristics and challenging behaviour groups.

NCB= No challenging behaviour CB= Challenging behaviour

		NCB (n=14)	CB (n=37)	t/Z/X₂	p-value
Age	Mean (SD)	18.92 (10.29)	12.51(3.93)	2.27	0.02*
Gender	Male	11 (78.6%)	33 (89.2%)	0.97	0.33
Verbal		13 (92.9%)	31 (83.8%)		
Mobile		14 (100%)	37(100%)		
Wessex self help		8.5 (0.75)	6.93 (1.5)	3.70	0.001**
<i>Social Communication Questionnaire Subscales</i>					
Communication		8.45 (2.22)	8.38 (2.23)	0.11	0.91
Restricted, repetitive & stereotyped behaviour		4.59 (2.00)	5.62 (1.93)	-1.68	0.99
Reciprocal interaction		6.78 (2.86)	8.80 (3.14)	-2.10	0.04*
<i>Mood Pleasure and Interest Questionnaire Subscales</i>					
Mood		19.64 (3.29)	18.36 (3.66)	1.13	0.26
Pleasure & interest		17 (4.73)	13.64 (4.46)	2.35	0.02*
<i>Repetitive Behaviour Questionnaire Subscales</i>					
Stereotyped behaviour		5.50 (4.32)	6.56(4.15)	-0.81	0.42
Compulsive behaviour		8.67 (7.72)	8.51 (7.15)	0.07	0.94
Insistence on sameness		4 (2.98)	4.21(2.69)	0.24	0.81
Restricted preferences		5.23 (2.89)	4.96 (3.64)	0.23	0.82
Repetitive language use		5.30 (4.26)	6.03 (4.12)	-0.53	0.60
<i>Activity Questionnaire Subscales</i>					
Impulsivity		14.07(6.62)	18.02 (5.6)	-2.13	0.03*
Overactivity		16.64 (3.29)	19.18 (9.99)	-1.05	0.30
<i>Maternal Wellbeing Scales</i>					
Depression (HADS)		6.5 (4.98)	7.65 (4.04)	0.85	0.39
Stress (QRSF)		4.11 (2.34)	5.67 (1.63)	2.34	0.01**

Note: *significant at 0.05 level
 **significant at 0.01 level

3.3. Person Characteristics and their Relation to Parental Stress

To address the study's second aim of exploring the relationship between challenging behaviour parental stress and person characteristics, Spearman's Rho correlations were first derived and the results are shown in Table 2.2. This analysis indicated that adaptive functioning, pleasure and interest, reciprocal interaction and impulsivity, were correlated with stress. Adaptive functioning and interest and pleasure were found to have moderate negative correlations with stress, where higher levels of adaptive functioning and pleasure and interest is related with lower levels of stress (Wessex, $r=-0.34$ $p<0.05$; pleasure and interest, MIPQ, $r=-0.34$, $p<0.05$). Impulsivity was found to have a moderate positive correlation with stress, (AQ, $r=0.38$, $p<0.01$) where elevated impulsive behaviours are associated with higher levels of stress. Reciprocal interaction evidenced a small positive correlation with stress, ($r=0.28$, $p<0.05$), where higher levels of impairment in the ability to have social reciprocal interaction relates with higher stress levels in parents.

Given that there is a significant difference in levels of adaptive functioning, pleasure and interest, reciprocal interaction and impulsivity between groups of challenging and no challenging behaviours and that these same variables correlate with parental stress, a regression analysis was completed to explore whether any of the correlated person characteristics were predictive of parental stress.

Table 2.2: Variables correlated with scores of parental stress.

Variable	Parental Stress (N=51) Spearman Rho Correlations
Age	-0.06
Wessex self help	-0.34*
<i>Social Communication Questionnaire Subscales</i>	
Communication	0.33
Restricted, repetitive & stereotyped behaviour	0.09
Reciprocal interaction	0.28*
<i>Mood Pleasure and Interest Subscales</i>	
Mood	-0.27
Pleasure & interest subscale	-0.34*
<i>Repetitive Behaviour Questionnaire Subscales</i>	
Stereotyped behaviour	0.27
Compulsive behaviour	0.12
Insistence on sameness	0.26
Restricted preferences	0.21
Repetitive language use	0.24
<i>Activity Questionnaire Subscales</i>	
Impulsivity	0.38**
Overactivity	0.25
<i>Maternal Wellbeing Scales</i>	
Depression (HADS)	0.31*

Note: * correlation is significant at 0.05 level (2 tailed)

**correlation is significant at 0.01 level (2 tailed)

3.4. Variables Predictive of Parental Stress

A binary logistic regression analysis was used to examine the relationship between person characteristics, challenging behaviour and parental stress. Based on the first two analyses the predictor variables in the regression were adaptive functioning, reciprocal social interaction, impulsivity and pleasure and interest. These variables were included in the model as they were significantly correlated with parental stress and were found to be significantly different between challenging behaviour groups. Challenging behaviour groups was the fifth predictor entered into the model. The results are presented in Table 3.1.

A test of the predictor model against the constant model was significant, ($\chi^2(5) = 12.04, p = 0.03$). The Hosmer and Lemeshow Test was also completed, which is the most reliable test model of fit (Pallant, 2005). For the model to have a goodness of fit, outcome on the Hosmer and Lemeshow Test must be above usual levels of significance, and this was the case ($\chi^2 = 11.62, p = 0.17$). A Cox & Snell R Square test and Nagelkerke R Square Test were also run to provide an indication of the amount of variation in the dependent variable explained by the model. The Cox and Snell test had an R Square value of 0.21, indicating 21% of variance to be explained by the model, whereas the Nagelkerke R Square value was 0.29, indicating that the model would explain 29% of variance. As the tests demonstrated that the model was worthwhile, the binary regression analysis with the five independent variables was completed.

The predictor model improved the amount of variables predicted correctly by the constant model (constant model = 56%, predictor model = 66%). For the low stress group 50% were correctly predicted and for the high stress group 78.6% of cases were correctly predicted. The Wald criterion showed the only significant predictor variable in the model to

be impulsivity, Wald= 3.84, $p=0.05$, $df=1$ and this is on the margin of significance. As a positive predictor variable, an increase in impulsivity will make it more likely for a parent to be stressed. The odds ratio of having a child exhibiting impulsivity which will make it more likely that a parent will be stressed is $EXP(B) = 1.12$. Each time impulsivity increases by one unit, the odds of parental stress increase 1.12 times. However, it should be noted that this is marginally significant with confidence intervals at 95% are 1.00-1.25.

Table 3.1: Results of binary regression logistic analysis with five predictor variables

	B	S.E	Wald	df	Sig.	Exp(B)	95% C.I for EXP(B)	
							Lower	Upper
Challenging behaviour group	-1.04	0.84	1.53	1	0.22	0.35	0.07	1.83
Impulsivity	0.11	0.06	3.84	1	0.05	1.12	1.00	1.25
Pleasure and interest	-0.09	0.08	1.48	1	0.22	0.91	0.78	1.06
Adaptive functioning	-0.03	0.25	0.01	1	0.91	0.97	0.59	1.58
Social reciprocal interaction	-0.01	0.12	0.01	1	0.91	0.99	0.78	1.25
Constant	0.37	2.91	0.02	1	0.89	1.45		

4. Discussion

This study addressed two aims. First was the hypothesis that participants with autism spectrum disorder showing challenging behaviour will evidence more prominent characteristics associated to autism. Adaptive functioning, reciprocal social interaction, communication, mood, pleasure and interest were expected to be more impaired, and impulsivity, overactivity and restricted repetitive behaviours were expected to be more prominent in the group showing challenging behaviours. The second aim was to explore the relationship between challenging behaviour, person characteristics associated with challenging behaviour and parental stress. As expected based on previous literature, comparisons between the challenging behaviour and no challenging behaviour groups supported the first hypothesis. The person characteristics of adaptive functioning, pleasure and interest and reciprocal social interaction were lower when challenging behaviours were present and impulsivity was higher. The challenging behaviour group was also younger.

In exploring the relationship between parental stress and person characteristics, correlations showed lower adaptive functioning, lower pleasure and interest and lower reciprocal social interaction were associated with higher parental stress. Higher levels of impulsivity were also found to be positively correlated with parental stress. Impulsivity was the only variable found to be predictive of stress in the regression analysis and this was on the margin of significance. Person characteristics of communication, mood, overactivity and repetitive, stereotyped behaviours did not differ significantly between the challenging behaviour and no challenging behaviour groups. These characteristics were not found to be associated with parental stress. Therefore, a new model of predictors of parental wellbeing is outlined in Figure 2.1, which emphasises impulsivity as the main predictor.

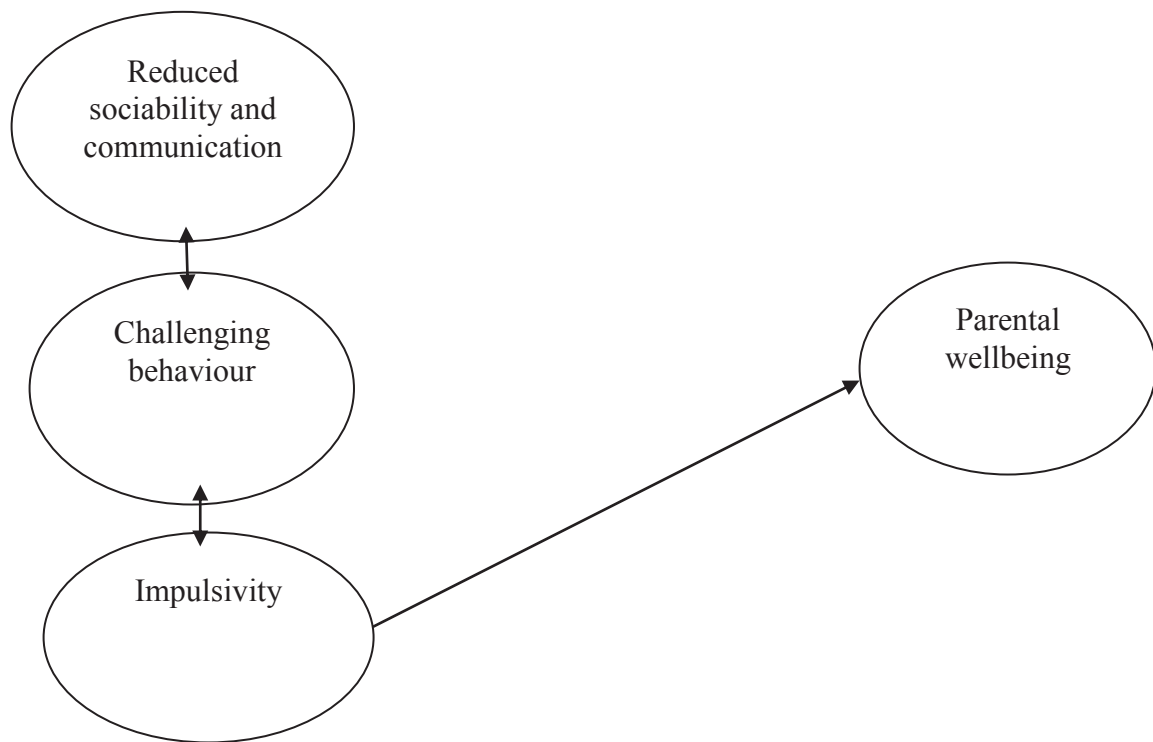


Figure 2.1: Model of participant characteristics and how they interact to predict parental wellbeing

Lower levels of adaptive functioning have been consistently associated with autism spectrum disorder (Liss et al., 2001; Kenworthy, Case, Harms, Martin & Wallace, 2010; Hartley et al., 2008; Matson, Rivet, Fodstad, Dempsey, & Boisjoli, 2009b; Matson & Shoemaker, 2009) and in this study, adaptive functioning is lower when challenging behaviour is evident. Whilst studies have found that adaptive functioning worsens with the presence of psychiatric co-morbid presentations (Matson et al., 2009b) and is associated with lower IQ (Liss et al., 2001; Kenworthy et al., 2010) no studies to date focus on the difference in adaptive functioning when there is the presence of challenging behaviours. However, the finding that lower adaptive functioning is associated with higher parental stress is replicated in other studies (Cohen & Tsiouris, 2006; Hall & Graff, 2011).

Pleasure and interest derived from the surrounding environment and poorer reciprocal social interaction are, arguably, both characteristics of autism spectrum disorder. Both traits were associated with stress and differed between challenging behaviour groups. Arron et al. (2011) also found lowered pleasure and interest in genetic groups showing self-injurious behaviours, and in groups showing aggressive behaviours, reciprocal social interaction was lowered. This is consistent with other research showing that prosocial behaviour is a negative predictor of maternal stress, so the more prosocial behaviour that is encountered, the less stress is experienced (Beck, Hastings, Daley & Stevenson, 2004).

Overactivity, was not related to the presence of challenging behaviours or parental stress, whereas impulsivity was found to be higher in those with challenging behaviours and is the only predictor of maternal stress from the results of the regression analysis. Impulsivity has been found to be related to challenging behaviours in people with intellectual disabilities (Villa et al., in preparation; Rojahn, Matson, Naglieri, & Mayville, 2004; Oliver, Sloneem, Hall, & Arron, 2009). Arron et al. (2011) also found that overactivity and impulsivity was higher in a number of people with genetic disorders when aggression and self-injury were present, and a similar result was found by Oliver et al. (2010).

Impulsivity may be more difficult for parents to cope with than challenging behaviours alone or other person characteristics, as the nature of impulsivity may make it difficult for parents to plan and implement coping strategies and interventions. Long term this may undermine parental confidence in their abilities. Recent studies that separate impulsivity from other traits have found a negative impact of impulsivity on parents (Bostrom et al., 2010).

Repetitive, restricted, compulsive and stereotyped behaviours were not found to be associated with challenging behaviours or parental stress in this study. Previous research has found restricted and repetitive behaviours to be associated with challenging behaviours (Shattuck et al., 2007; Murphy et al., 2009; Davies, 2009, Villa et al., in preparation) and parental stress (Bishop, Richler, Cain, & Lord, 2007). However, repetitive and restricted behaviours may not be associated with challenging behaviours in this study because all participants show repetitive and restricted behaviours as the presence of these behaviours are related with autism spectrum disorder.

Age was a significant variable in this study, with younger children showing more challenging behaviours. Age has been an inconsistent factor in the literature with some studies finding that challenging behaviours and self injury are more prevalent in younger people with autism (Baghdadli et al., 2003; Holden & Gitlesen, 2006) and other studies finding no changing relationship between age and challenging behaviours (Murphy et al., 2009; Matson et al., 2010; McTiernan et al., 2011) . Other research has found a decrease in the rate of challenging behaviours and stereotypy as age increases (Shattuck et al., 2007).

This study has extended the literature by not only supporting literature that has previously evidenced more prominent autistic characteristics where there is the presence of challenging behaviours and relating challenging behaviours with parental stress, but also by showing that person characteristics, in particular impulsivity also relate to parental stress, rather than the challenging behaviour alone. This warrants further investigation.

4.1. Strengths and Limitations of the Study

The strengths of this study are the comprehensive evaluation of relevant person characteristics (adaptive functioning; mood, interest and pleasure; repetitive, restricted and stereotypical behaviour; social interaction and communication; impulsivity and overactivity) using measures adapted for people with intellectual disability.

The group was reasonably homogenous as all participants live in the parental home. The parental sample consists of mothers, as inclusion of fathers may have confounded the overall findings, given that there are differences in father and mother perceptions and stress and depression levels (Hastings et al., 2005b; Hastings et al., 2005a; Tehee et al., 2009; Kayfitz et al., 2010). The sample is reasonably well defined by assessment and evaluation on the SCQ. Although this is not a diagnostic assessment it is the most widely used screening measure and would allow replication.

The main limitation of this study is the small sample size. The limited sample size is especially pertinent in line with the regression model, where each predictor variable had 10 participants. The power of the model could have been increased with more participants. Therefore, impulsivity as a predictor for stress, especially given the confidence intervals, warrants further investigation. The large variance in participants' age could also be viewed as a weakness of the study. However, if age groups were made more homogenous, the sample sizes would have been further reduced and statistical power and analysis compromised.

The participants showed different types of challenging behaviours (e.g. aggression, self injury, property destruction). However due to the sample size, groups showing different types of behaviour were too small to act as comparison groups to one another. This meant

that participants were grouped as showing a type of challenging behaviour or not. If groups were large enough to act as comparators to one another, challenging behaviour type and person characteristics could have been explored. Similarly, parental stress in relation to different types of challenging behaviours could also have been explored.

The measure used to assess parental stress was a reduced measure of the QRSF. The reduced measure has been found to have good reliability and validity (Griffith et al., 2011), although it has not been widely used, and may not be as effective as the full scale. However, using a reduced measure was more user friendly for the parent completing the questionnaires. The depression scale of the HADS was used to measure parental depression, and although depression was not found to significantly differ between challenging and no challenging behaviour groups, given other literature which has found a relationship between autistic characteristics and depression (Meltzer, 2011), further exploration into adult mental health difficulties in relation to person characteristics may be beneficial.

The parent participant group were high in economic and educational attainment. This may eliminate other confounding stressors, such as financial hardship, however a more diverse sample of participants would allow further generalisability of the results.

4.2. Clinical Implications and Future Directions

The results of this study are preliminary but are supportive of other studies that have begun to recognise the role of impulsivity in both challenging behaviours and parental stress (Villa et al., in preparation; Bishop et al., 2007; Davies, 2009; Arron et al., 2010; Oliver et al., 2010; Bostrom et al., 2010). Clinically, it would be helpful to recognise impulsivity when considering interventions to help with challenging behaviour and parental stress, as it

may complicate systematic coping or intervention strategies that parents may use. However, the role of impulsivity needs further exploration in relation to challenging behaviours, person characteristics and parental wellbeing.

As this study had a limited number of participants, it would be useful to replicate the study with a larger number of participants in order to compare results. In addition, restricted age bands would make the methodology stronger.

Overall, further research needs to be undertaken in assessing individual autistic characteristics and their relationship to challenging behaviours and parental stress. From this study, impulsivity, social aspects such as reciprocal social interaction and pleasure and interest and adaptive ability are especially pertinent to consider in future research.

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PUBLIC DOMAIN BRIEFING DOCUMENT

Overview of the Literature Review and Empirical Paper for Dissemination to the Public

Public Domain Briefing Paper

Outline

The research outlined in this paper has been conducted by Sarah Weaver, Trainee Clinical Psychologist at the University of Birmingham, as a partial requirement to the completion of a Clinical Doctoral degree (DClinPsy).

Overview of Literature Review

‘Positive Impact and its Relationship to Wellbeing in Parents of Children with an Intellectual Disability’

Background

Research has primarily focused on stress, depression and other mental health difficulties encountered by parents caring for children with intellectual disabilities. Whilst this research is useful, there is little acknowledgement of the positive impact of caring on parents.

Aims

The literature review had three aims. First, to identify themes about the positive impact of caring for people with intellectual disabilities. These themes were identified from research that used interviews and questionnaires with parents. Second, the review aimed to look at some of the questionnaire measures used in studies, and to explore the types of positive

impact the questionnaires assessed. Third, the review aimed to look at the relationship between positive impact and mental wellbeing in parental carers.

Results

The study found fourteen themes that parents identified as positive impacts of caring. These themes focused on the positive emotions of the parent, increased empathy for other people, rethinking life values and an emphasis on their child's achievement. There were two main questionnaire measures used that assess the positive impact of caring. These were called The Kansas Inventory of Positive Perceptions, which assessed positive perceptions of caring, and the Positive and Negative Affect Scale, which assessed emotions.

When looking at the relationship between the positive impact of caring and parental wellbeing, the presence of positive impact was related to improved wellbeing. The study draws attention to other factors that may affect the relationship between the positive impact of caring and parental wellbeing. These are; mother and father differences in wellbeing and sense of positive impact, the type of syndrome or disability that the child has, and whether or not the child has challenging behaviours. Parental differences also seem to affect the relationship between positive impact and wellbeing, for example with parents using different coping strategies and different levels of parental self-esteem.

Conclusions

The review concludes that a definition of positive impact relating to caring for people with intellectual disabilities would be helpful, and a model to explain how positive impact is

utilised would be useful. In order to do this further research into positive impact, parental wellbeing and other factors is needed.

Overview of Research Paper

‘Autism Spectrum Disorder, Challenging Behaviours and Maternal Stress’

Background

Parents who care for children with intellectual disabilities tend to experience more stress. There is evidence to suggest that this is because people with intellectual disabilities show more types of challenging behaviours, such as aggression and self-injury. In parents who care for children with autism spectrum disorder, their stress is higher still. Challenging behaviours are even higher in people with autism spectrum disorder than in people with other types of intellectual disability. Research has shown that the more severe the autism spectrum disorder is the more severe challenging behaviours are. Recent research has suggested that stress in parents, may not only be due to their child’s challenging behaviours, but may also be because people with autism spectrum disorder show other characteristics which parents may find difficult. Types of characteristic that people with autism spectrum disorder may show are lower levels of self-care skills, lower levels of shared social interaction, poorer communication skills, lower mood and lower pleasure and interest in activities. Individuals with autism spectrum disorder may also show repetitive and obsessive behaviours, where a child may be unable to deviate from an activity or routine. Higher levels of overactivity and impulsivity may also be present in people with autism spectrum

disorder. These types of characteristic have been found to be more severe in people with autism spectrum disorder who show challenging behaviours.

Aims

Taking into account the research, the study had two aims. The first one was to explore whether autistic characteristics were higher in people with autism that showed challenging behaviours. The second aim was to explore the relationship between autistic characteristics, challenging behaviours and parental stress.

Participants

Participants were 51 individuals with autism spectrum disorder and their mothers.

Individuals with autism spectrum disorder ranged in age from 6 years to 49 years.

Participants were contacted as they had previously taken part in similar research with the University of Birmingham and they had agreed for their details to be held by the University so that they could be contacted again for follow up research.

Procedure

Parents of individuals with autism spectrum disorder received a letter explaining the aims of the study. They also received a consent form that confirmed they agreed to their children and themselves to take part in the study. They filled in questionnaires about their children with autism spectrum disorder, about the family and about their wellbeing. They returned

the questionnaires in a stamped addressed envelope. In return for taking part, parents received a report giving the outcomes of the questionnaires they filled in.

Findings

When participants with autism spectrum disorder showed challenging behaviours, characteristics including the child's self care skills, pleasure and interest and shared social interaction were lower than in participants who did not show challenging behaviours. The characteristic of impulsivity was higher in participants that did show challenging behaviours. Participants who showed challenging behaviour were lower in age than participants who did not show challenging behaviour. Repetitive and obsessional behaviours, mood and overactivity were autistic characteristics that were not different when challenging behaviour was shown.

When looking at characteristics that were associated with parental stress, higher impulsivity and lower pleasure and interest, poorer self-help skills and lower shared social interaction were found to be linked with stress. Repetitive and obsessional behaviours, mood and overactivity were not found to be related with parental stress. Impulsivity was the only characteristic that was found to predict parental stress.

Summary and Conclusions

Some autistic characteristics are worse when challenging behaviour is present. A focus on this is important, so that when professionals try to help parents cope, parents and professionals can focus on the challenging behaviour and the autistic characteristics, such as

lower pleasure and interest and heightened impulsivity. This may help to lower parents' overall stress.

The study does support other recent literature that has started to look at impulsivity in children with autism spectrum disorder and recognise its importance. Impulsivity in children may be difficult for parents to cope with as there is no pattern to their children's routines or behaviours, which may feel stressful for the parent. However, more knowledge is needed about how impulsivity along with other autistic characteristics may interact with challenging behaviours and parental stress.

Appendix 1

Tables Used in the Literature Review

- 1.1: Complete table of papers used in the literature review in alphabetical order**
- 1.2: Quality review of qualitative articles included in the review based on Sale and Brazil's (2004) critical appraisal criteria**
- 1.3: Quality review of quantitative articles included in the review based on Sale and Brazil's (2004) critical appraisal criteria.**

Appendix 1.1. Complete table of paper used in the literature review

Appendix 1.1: Complete table of papers used in the literature review presented in alphabetical order.

ID= intellectual disability, ASD= autism spectrum disorder, DS= down syndrome, TD= typically developing, CB= challenging behaviour

Reference	Sample	Assessed	Measures	Findings
Altieri & Von Kluge(2009)	26 married couples. Children with ASD, boys n= 23, girls n=3 (age range 3-16yrs).	Investigates the early development of the child, social support within the family and beliefs of parents about the causes of their child's autism. It examines parents' positive experiences and changes that may have resulted from raising a child with autism.	Semi structured interview analysed with grounded theory analysis.	Main themes: <ul style="list-style-type: none"> - Development of the child and the autism. - Questioning what is happening to their child. - Confusing symptoms, such as challenging behaviours. - Looking for answers and explanations of the autism. - Devastation at the diagnosis. - Loss of support from others. - Personal struggles such as financial hardship. - Solutions found through hope and knowledge. - Treatments and therapies their child became involved in. - Attribution of causes of autism. - Personal growth; personal benefits such as emotional and spiritual growth. - Family benefits such as support and closeness. - Child benefits including attributes and achievements .
Al Yagon & Margalit (2009)	Two groups. Group 1 n=95 mothers. 95 children with ID. Boys n=47, girls n=48 (age range 2-39 months). DS, n= 68. Group 2 n=104 mothers. 104 children with ID. Boys n= 55, girls n=49 (age range 7.5 – 21.3 yrs) DS n= 48.	The study focuses on maternal resources, family vulnerability and protective resources to help explain the differences in mothers negative and positive affect. Also investigates the effect of child age and the difference between DS and other IDs.	<ul style="list-style-type: none"> - Affect Scale (Moos et al, 1987). - Parenting Stress Index Short Form (PSI-SF, Abidin, 1990). - Coping Scale (Mbos et al., 1987). - Sense of Coherence Scale (SOC, Antonovsky, 1987). - Hope Scale (Snyder, 2002). - Family Adaptability and Cohesion Evaluation (Olson et al, 1985). 	Mothers whose children were in group 1 (early intervention programme) compared to those in group 2 (respite care) had lower feelings of distress and unhappiness. Mothers in group 1 reported lower perception of family's adaptability than mother's in group 2. No significant differences emerged in maternal and family vulnerability and protective variables among mothers of children with DS versus mixed IDs. A regression analysis indicated a high level of maternal positive affect was associated with low scores on maternal stress, a high level of maternal sense of coherence (SOC), a high level of maternal active coping strategies, high level of perception of family cohesion, and a high level of maternal hope. High levels of maternal negative affect were associated with children's affiliation to the early intervention programme, high scores on avoidant coping and a low level of maternal SOC.

Blacher & Baker (2007)	Two studies. Study 1- n=282 mothers (age range 31-70 yrs) of children with ID (age range 16-26yrs). 150 mothers Anglo and 132 Latino. Study 2- n= 214 families of children with ID, n=82, borderline ID n=10, TD, n= 122, (age range 3-5yrs).	Study 1 examines the relationship between well being and positive perceptions and whether mothers' perceptions are related to CB or mental health problems. Examines moderator effects of positive perceptions on maternal well being and CB. Study 2 examined parents perceptions of positive and negative impact and how this is related to CB, parent gender and culture. Moderator effects of parental positive perceptions on the relationship between CB and parental wellbeing for mothers and fathers were explored.	Study 1 <ul style="list-style-type: none"> - The Vineland Adaptive Behavior Scales (Sparrow, Balla, & Cicchetti, 1984). - The Family Impact Questionnaire (FIQ; Donenberg & Baker, 1993). Center for Epidemiological Studies-Depression scale CES-D (Radloff, 1977). - Scales of Independent Behavior-Revised Problem Behavior Scale SIB-R (Bruininks, Woodcock, Weatherman, & Hill, 1995) - The Reiss Screen for Maladaptive Behavior, 2nd ed. (Reiss, 1994). Study 2 <ul style="list-style-type: none"> - Bayley Scales of Infant Development II (Bayley, 1993). - Stanford Binet Intelligence Scale IV (Thorndike, Hagan, & Sattler, 1986). - Child Behavior Checklist for Ages 1½-5 CBCL (Achenbach, 2000). 	Study1 Positive impact was not correlated with depression. CB and mental health impact increased negative impact in Latino and Anglo samples. Positive impact reduced significantly when high CB and/or mental health scores were present in Anglo and Latino samples. Higher positive impact somewhat buffered the increase in stress that accompanies CB. Study 2- Positive impact was not correlated with depression. The severity of intellectual disability had no impact on positive perceptions, CB were however associated with lower positive impact for mothers and fathers. Fathers showed greater positive impact than mothers when assessed at child ages of 3, 4 and 5yrs. Latino parents had higher positive impact than Anglo parents did, but this was not significant, however there was a significant interaction between culture and ID. In the TD group, positive impact was the same for Anglo and Latino mothers. In the ID group, Anglo mothers expressed lower positive impact than Anglo mothers in the TD group did, whereas Latina mothers expressed higher positive impact than did Latina mothers in the TD group. Latino fathers reported marginally higher positive impact than Anglo fathers and there was a similar interaction between culture and ID group although it was not significant. There was a strong relationship between CB and mothers and father negative impact and parenting stress. Positive impact had a moderator effect on stress for mothers and fathers.
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Blacher & McIntyre (2006)	150 anglo and 132 latino mothers of n= 282 young adults with ID. Four diagnostic groups, DS, ASD, cerebral palsy and mixed/ or unknown ID.	Investigates if mental disorders and CB differ across diagnostic groups, whether parental wellbeing changes and whether there is a difference between Anglo and Latino parents.	<ul style="list-style-type: none"> - Acculturation Scale for Hispanics (Marin et al., 1987). Vineland Adaptive Behaviour Scales (Sparrow et al., 1984). - Scales of Independent Behaviour – revised problem behaviour scale (SIB-R, Bruininks et al., 1996). - Reiss Screen for Maladaptive Behaviour (Reiss, 1994). - Family Impact Questionnaire (Donenberg and Baker, 1993). - Center for Epidemiological Studies- Depression (CES-D, Radloff, 1997). - Philadelphia Geriatric Center Morale Scale (Lawton 1972) for general morale/ mood. 	Overall behaviour problems and mental health problems were high across groups. The highest levels of behaviour problems were found in autism and lowest in Down Syndrome. The Cerebral Palsy group were low in behaviour problems and not significantly different to Down Syndrome. Latino and Anglo samples were similar in level of behaviour problems scores, percentage in clinical range and pattern of scores across diagnostic groups. The relationship between diagnostic group and maternal wellbeing was almost entirely accounted for by the level of behaviour problems. A diagnosis of Down Syndrome also had a small effect on positive impact. Depression was significantly higher and morale significantly lower in Latino mothers however stress levels did not differ. There was a much higher report of positive impact in Latino mothers than Anglo mothers, which may indicate different attributions or personality characteristics between groups.
Bostrom, Broberg & Hwang (2009)	Mother n=8, fathers n=9 of children with ID (age range 9 mths - 9 yrs).	Aims to discover how parents describe their experiences and the childhood disability.	Interviews analysed with Phenomenological Interpretative Analysis (IPA).	<p>Main themes:</p> <p>Parents emotional expressions regarding the child: positive/ affectionate, loving descriptions of the child, balanced descriptions of child negative and positive characteristics, usually emphasis on positive, well functioning routines, parent child interaction and the child as an individual. On the negative side some parents had mainly negative descriptions, and indicated ambivalence and distance toward the child.</p> <p>Idealisation was characterised by overly positive descriptions, where there were inconsistencies in the interview, and a lack of negative description.</p> <p>Experience of the disability was characterised by; acceptance, minimal focus on disability, reflection on emotional change, balanced descriptions of how disability affected parents lives. There was also preoccupation with the disability which focused on lack of diagnosis or disagreement about diagnosis, child's disability in relation to the rest of the world, traumatic events and severe disability.</p> <p>There were also differing time orientations noted with some narratives having a preoccupation with past and present, some being preoccupied with past or present but making attempts to speak about the future and others that moved freely between different time domains.</p>
Bostrom, Broberg & Hwang (2010)	Mothers n=55, fathers n=44 of children with ID (age range 5- 79 months). TD age matched children n= 183.	Aim to investigate mothers and fathers subjective descriptions of child temperament and positive/ negative impact of children with and without ID. Also aims to compare parents descriptions of temperament as well as positive and negative subgroups, defined by diagnosis. It also looks the difference between mother and father ratings.	<ul style="list-style-type: none"> - EASI Temperamental Survey (Buss & Plomin 1984; Hagekull & Bohlin 1990). - Two sub-scales from the Family Impact Questionnaire (FIQ, Donenberg & Baker 1993). 	When compared to the control group children in ID group rated higher on shyness and impulsivity and lower on activity and sociability. There was no difference for emotionality. Children with ID rated lower on the positive scale and higher on negative scale in comparison with TD group. Negative impact positively correlated with emotionality in all groups and with impulsivity in the ID group. Positive impact was negatively correlated with emotionality for the TD group and impulsivity for children in ID group. Children with DS had lower levels of emotionality than general ID, ASD and other diagnosis. Children with cerebral palsy (CP) and motor impairment (MI) differed significantly from the ASD group. The ASD group rated significantly higher on shyness compared with the DS group and lower than all groups on sociability scale. Children with ID had the highest level of impulsivity. Overall children with DS had less negative impact on parents than children with ASD and children with CP/MI had less negative compared with ASD and ID groups. Age did not alter temperament in groups apart from in the TD group where impulsivity differed across ages. Mother and father differences- when comparing ratings for child temperament no significant differences were found in mothers and fathers, nor did negative and positive emotions differ towards the child.

Corman (2009)	Mothers n=9 of children with ASD (age range 8-18 yrs).	To examine mothers positive perceptions.	Interviews.	Main themes Pockets of child development, developmental gains, child being happy, times devoid of negative traits or maladaptive behaviours, spending time together, unique and/or positive personality traits associated with the child, knowing or discovering what was wrong with their child.
Ekas & Whitman (2010)	Mothers n=119 (age range 23-61 yrs) with a child with ASD (age range 2-18yrs) predominantly male (82.9%).	Study aims to look at the impact of symptoms and CB of mothers socio-emotional functioning including positive perceptions.	<ul style="list-style-type: none"> - Childhood Autism Rating Scale (CARS, Schopler, Reichler, DeVellis, & Daly, 1980). - Autism Severity Index (ASI, Benson, 2006). - Child Related Stress Scale (created by authors, 5 item likert scale scoring). - Parenting Stress Index-Short Form (PSI-SF, Abidin, 1990). - The Center for Epidemiologic Studies Depression Inventory (CES-D, Devins et al., 1988; Radloff, 1977). - The Positive and Negative Affect Schedule (Watson, Clark, & Tellegen, 1988). - The Satisfaction With Life Scale (Pavot & Diener, 1993). - The Psychological Well-Being Scale (Ryff & Keyes, 1995). 	In general compared to low risk samples mothers reported high degrees of stress, higher negative affect and clinically diagnosable levels of depression. In comparison to low risk samples mothers reported lower positive affect and lower life satisfaction. Greater symptom severity (symptom frequency level and diversity) was significantly and positively related to stress, negative affect and depression. Mothers with more than one child with autism reported lower life satisfaction, lower wellbeing, greater negative affect and depression. Mothers who reported that their child displayed high frequencies and severity of their syndrome types reported higher levels of stress, depression and negative affect. Only one positive scale, life satisfaction was negatively associated with the various symptom types. In a hierarchical regression analysis after controlling for all other variables, behaviour problems accounted for child related stress, parenting stress and depression and the frequency of behaviour problems was found to predict child related stress, negative affect and parent stress. Overall autism symptomology was found to be a better predictor of maternal negative outcomes than positive outcomes.
Green (2007)	Mothers n=61 (mean age 35.5 yrs) of children (mean age 60.12 months) with disabilities (cerebral palsy 31%, DS 7%, Head Trauma 4% and general ID, 53%).	Addressed 4 questions. 1) Are perceptions of socio-structural constraints (objective burden) or emotional distress (subjective burden) more prevalent among mothers with ID? How are the constraints and emotional distress associated with caring described? 2) How do demographics and perceived stigma affect maternal perceptions of the objective and subjective burdens of care? 3) What are the benefits and how are they described? 4) How do demographics, stigma, objective and subjective burden affect the benefits?	<ul style="list-style-type: none"> - Perceived stigma was measured using an adaptation of the "Devaluation-Discrimination Scale (Link, Cullen, Struening, Shrot, & Dohrenwend, 1989). - Caregiver Burden was measured with an adaptation of the Burden Assessment Scale (Horwitz & Reinhard, 1995; Reinhard, Gubman, Horwitz & Minsky, 1994). - Maternal perceptions of the benefits were measured using five questions, rated on a likert scale which were developed for this study. 	<ol style="list-style-type: none"> 1) Mothers reported significantly higher levels of objective than subjective burden, indicating that mothers are likely to view the burden of caring in terms of socio-cultural constraints rather than emotional distress. Qualitative results pertaining to this indicate the amount of time the child spends with physicians or in treatment, which limit social activities and leisure time and emotional distress. 2) Mothers who work outside the home experience higher objective burden, especially where employers are not accommodating. Objective burden also increases with the amount of other children in the home. The severity of the child's disability has a relationship with objective burden but when other variables are introduced this disappears suggesting that there are other variables that act as mediating factors. Maternal education is negatively associated to objective burden and perceived stigma significantly increases objective burden. When looking at subjective burden regression analysis shows that perceived stigma has a strong positive impact on emotional distress. 3) Mothers rated highly on positive perceptions relating to pride and joy, growth from disability, being more understanding of others, gaining courage and strength and coping. 4) Younger mothers perceive greater benefits and benefits increase with age of the child. Perceived stigma or objective burden do not influence mothers' ability to find benefits in caring. Subjective burden however, reduces benefits. As stigma increases emotional distress which in turn decreases positive benefits, stigma has an indirect effect on benefits of caring.

Greer, Grey & McClean (2005)	36 female primary caregivers (age range 23-52yrs) of children with ID (age range 5-8yrs, male n=20, female n=16).	The aims of this study are to investigate whether, the severity of CB and emotional problems predicts perceived care demand. Secondly, whether perceived levels of care demand predict perceived helpfulness of informal and formal social support, thirdly whether helpfulness of informal and formal social support predicts cognitive and behavioural coping strategies and whether behavioural and cognitive coping strategies predict levels of positive perceptions.	<ul style="list-style-type: none"> - Demographic Questionnaire and Care Demand Scale (adapted from Hastings et al., 2002). - Developmental Behaviour Checklist-Parent Version (DBC-P: Einfield and Tonge, 1995). - Family Support Scale (FSS: Dunst et al., 1984). - Family Crisis Orientated Personal Evaluation Scales (F-COPES: McCubbin et al., 1991). - Kansas Inventory of Parental Perceptions (KIPP: Behr et al., 1992). 	64% of children were within the normal range for behavioural and emotional problems. 67% of participants rated their child as 'easy' or 'very easy' in terms of 'levels of care demand'. Mean helpfulness scores for perceived helpfulness of formal social support were only a little higher than scores for perceived helpfulness of informal social support. These results suggest that formal social support is as effective for mothers of children with ID. 78% of respondents rated agreement or strong agreement with statements that their child was: a source of happiness or fulfilment, 75% rated strength and family closeness, and 58% rated a source of personal growth and maturity. The severity of child behavioural and emotional problems significantly predicts perceived levels of care demand. Low ratings of severity of behavioural and emotional problems predicted low perceived levels of care demand. Perceived levels of care demand did not significantly predict perceived helpfulness of informal and formal social support. Thus, low levels of care demand did not predict perceived helpfulness of informal and formal social support. Perceived helpfulness of formal social support significantly predicted mobilising the family to acquire and accept help in the community.
Griffith, Hastings, Nash & Hill (2010).	Mothers n=57 of children with ASD (n=19), DS (n=19) and mixed diagnosis (n=19). The groups were matched demographically and on gender (girls n=18, boys n=39), age (age range, 4-18yrs) and communication score on VABS.	The study uses matched groups to explore child behaviour problems and maternal wellbeing.	<ul style="list-style-type: none"> - Vineland Adaptive Behaviour Scales (Sparrow et al., 1984). - Behaviour Problems Inventory (BPI; Rojhan et al., 2001). - Reiss Scales for Children's Dual Diagnosis (Reiss & Valenti-Hein, 1990). - Competence scale of the Nisonger Child Behaviour Rating Form (NCBRF, Aman et al., 1996). - Questionnaire on Resources and Stress Short Form (QRSF, Friedrich et al., 1983). - The Positive Contributions Scale from the Kansas inventory of parental perceptions (KIPP, Behr et al 1992). - Hospital Anxiety and Depression scale (HADS, Zigmond & Snaith 1983). - Positive Affect Scale (PANAS, Watson et al., 1988). - Life satisfaction measured with the Satisfaction with Life 	Mothers of children with ASD rated their children lower on social competence and higher on stereotypical and self-injurious behaviours than children in the other groups. The ASD group also were rated with higher levels of anger, anxiety, depression, low self-esteem, psychosis and withdrawn behaviours than the other groups. There were no significant differences between the DS group and mixed aetiology groups. Children with ASD were rated on having higher levels of aggressive/ destructive behaviours than mothers of children with DS. Mothers of children with ASD reported more stress than the DS. Mothers of children with DS scored higher on the positive contributions scale than mothers in ASD group. When child behaviour variables were introduced to the analysis the group difference on positive contributions was no longer significant when social competence or CB were controlled for. However, the group difference on stress remained the same.

Hastings, Allen, McDermott & Still (2002)	Mothers n= 41 of children with ID (age range 4-19yrs).	Purpose is to explore factors associated to positive perceptions and negative and positive feelings.	<ul style="list-style-type: none"> - Data gathered through a self-report questionnaire gathering demographic and care demand (to assess severity of impairment). - Family Support Scale (FSS,- Dunst et al., 1984) - Family Crisis Orientated Personal Evaluation Scales (F-COPES, McCubbin et al., 1991). - Positive contributions scale of the Kansas Inventory of Parental Perceptions (KIPP – Behr et al., 1992). 	The positive impact of the child (happiness and fulfilment) and the effect on the family in general (strength and family closeness) were positively predicted by the use of reframing coping strategies. Other potential predictors were not identified as making a significant independent contribution to these two domains. Reframing as a coping strategy was also a positive predictor of positive effects on the mother (personal growth and maturity). Several other factors emerged as positive predictors which were, helpfulness of informal social support, difficulty of caring for the child with a disability and acquiring social support coping. There was also a marginally significant negative impact of mobilising coping strategies.
Hastings, Beck & Hill (2005)	142 families (mothers n=140 fathers, n= 60) of children with ID (age range 4-18yrs).	Uses the positive contributions scale to assess the differences between mothers and fathers perceptions.	<ul style="list-style-type: none"> - Demographic questionnaire. Hospital Anxiety and Depression scale (HADS, Zigmond & Snaith 1983). Questionnaire on Resources and Stress Friedrich short form (QRS-F: Friedrich, Greenberg, & Crnic, 1983). - Positive and Negative Affect scale (Watson et al., 1988). - Positive contributions scale of the Kansas Inventory of Parental Perceptions (KIPP – Behr et al., 1992). 	The overall scores of the Positive Contributions Scale were found to have good convergent and discriminate validity. Mothers reported more positive perception in all subscales of the PCS apart from one. The subscales mothers reported higher on were learning through experience of special problems, source of happiness and fulfilment, source of strength and family closeness, awareness about future issues, personal growth and maturity, expanded social network, career/job growth. The subscale fathers reported more highly on was source of pride and cooperation.

Hastings, Kovshoff, Ward, delgi Espinosa, Brown & Remington (2005)	Mothers n= 48 and fathers n= 41(45 couples, 3 single parents) of children with ASD (age range 28-45 months).	Exploration of child characteristics, including behaviour, severity of ASD and adaptive function on parental wellbeing. Also explores whether maternal/ paternal wellbeing predicts the other partners wellbeing. It assesses whether parent wellbeing variables and child characteristics can predict positive perceptions .	<ul style="list-style-type: none"> - Parent Report version of the Developmental Behavior Checklist (DB-C—Einfeld & Tonge, 1995). - Adaptive behaviour measured with The Vineland Adaptive Behavior Scale—Survey Form (VABS, Sparrow, Balla, & Cicchetti, 1984). - Autism Screening Questionnaire (ASQ—Berument, Rutter, Lord, Pickles, & Bailey, 1999). - Hospital Anxiety and Depression scale (HADS—Zigmond & Snaith, 1983). - Questionnaire on Resources and Stress Friedrich short form (QRS-F: Friedrich, Greenberg, & Crnic, 1983). - Kansas Inventory of Parental Perceptions Positive Contributions scale (KIPP-PC: Behr, Murphy, & Summers, 1992). 	Mothers reported significantly higher levels of depression and significantly more positive perceptions than fathers. There were no significant correlations between the child's adaptive measures and parental wellbeing, although the mothers rating of their perception of the severity of the ASD was correlated with their own stress ratings, no correlations were found with the ASQ and parental wellbeing measures. Mothers' ratings of behaviour positively correlated with level of anxiety, stress and depression but not with positive perceptions. Fathers' perceptions of CB correlated with their own and with their partners stress. There were a number of inter correlations; mothers positive perceptions were not related to fathers wellbeing, but fathers positive perceptions were negatively correlated with their partner's stress and depression. Also, mothers stress scores were positively correlated with fathers depression and fathers stress was positively correlated with maternal anxiety and depression. A regression analysis found that child behaviour and paternal depression were significant predictors of maternal stress. For fathers, for stress and positive perceptions child variables did not account for variance and were not significant independent predictors however, maternal depression was.
Kayfitz, Gragg & Orr (2010)	23 mother /father pairs raising children with ASD (age range 5 to 11 years, mean =7.39).	The difference between mothers and fathers perceptions, with a focus on parents positive experiences and parental stress.	<ul style="list-style-type: none"> - Demographic questionnaire. - The Parenting Stress Index—Short-Form (PSI-SF) (Abidin, 1995). - Positive Contributions Scale (PCS) from the Kansas Inventory of Parental Perceptions (Behr et al., 1992). 	Mothers were significantly higher on the positive contributions composite and on the following subscales of the PCS- 1) learning through experience of special problems, 2) strength and family closeness 3) understanding life's purpose and 4) expanded social network. There was no significant difference for distress. 26% of parents (35% mothers, 17% fathers) reported clinically significant levels of distress. Mothers and fathers reports of total positive experiences were negatively related to their levels of parental distress. Mothers and fathers parental distress scores were significantly positively related to each other. Fathers reporting more positive experience were significantly negatively associated with their partner's reporting of parental distress.

King, Zwaigenbaum, King, Baker, Rosenbaum & Bates (2005)	A focus group consisted of 12 mothers and 3 fathers of children with ASD or DS and 4 service providers in the disability field.	The objective was to examine reported changes in belief systems of families of children with ASD and DS.	Qualitative analysis of focus group.	Main themes found from the analysis were: 1) Initial Reactions to Parenting a Child with a disability with sub themes of a) Life changing experience, b) lost dreams. 2) Adapting over time, with sub themes of a) Being spurred to examine beliefs, b) Importance of hope and seeing possibilities ahead, c) Gaining a sense of control and empowerment. 3) Changes in worldviews and values, with sub themes of, a) Stronger values and broader worldviews, b) Areas of personal growth, c) Learning what is important in life. 4) Changes in priorities, with sub themes of, a) Giving up trying to 'fix' the child, b) Refocusing on the needs of other family members.
Larson (2009)	39 parents (95% mothers 5% fathers age range 26-50 yrs) of children with ID(ASD, 28%, speech delay or oral dyspraxia, 19%, cerebral palsy, 14%, medically fragile, 12%, or genetic conditions, 23%).	To assess the level of wellbeing and how different wellbeing groups perceive caring for children with ID.	- Qualitative interview. - The Psychological Well-Being (PWB) scales (Ryff, 1989; Ryff & Singer, 2006).	From the PWB scales participants were categorised into 3 wellbeing groups High= 14, average= 12 and low = 13. Differences in well-being were not associated with income, education, or depressive symptoms. The qualitative analysis revealed one global meaning dimension for care giving (broadening of self, family, and world) and five situational level meaning categories of care giving (intensity of care giving, diminished personal control, perspective on care giving demands, depth of conviction about the value of this life course, and present dwelling). For the global meaning, triangulation between the PWB scales and the qualitatively generated themes confirmed that there were differences between the high and low well-being groups. Findings suggest that 75% of caregivers describe frequently challenging care giving demands. Participants who rated highly in well being constructed a more positive view of the meaning of this experience, which may broaden their capacity for care giving.
Mak & Ho (2007)	212 Chinese mothers (mean age 42.84yrs) of children with ID, (mean age 12.65yrs) with diagnoses of ASD (46.2%), moderate disability (25.9%) and mild disability (69.3%).	Investigates emotion focused coping, relationship focused coping and problem focused coping and the relationship to negative and positive perceptions. It accounts for effects of demographics, perceived stress and social support.	- Demographic questionnaire. - Daily caregiving stress (Hastings et al., 2002). - The Modified Family Support Scale (FSS; Dunst et al., 1984). - Eight subscales of the COPE Inventory (Carver et al., 1989). - Relationship-Focused Coping Scale (DeLongis & O'Brien 1990). - Negative perceptions were measured by the Chinese version of the Caregiver Burden Inventory (Novak & Guest, 1989). - Four subscales of the Kansas Inventory of Parental Perceptions (KIPP) were adopted to measure positive perceptions (Behr et al., 1992).	Emotion-focused coping was positively related to negative perceptions and problem focused coping and relationship focused coping were related to positive perceptions. Emotion focused coping had no significant relationship with problem focused coping and a weak relationship with relationship focused coping. However problem focused coping and relationship focused coping were moderately related to one another. The presence of ASD and severity of ID were significantly related to mothers' negative perceptions, however the influence dropped when other stress variables were accounted for. The higher the stress, the stronger mother's negative perceptions about caregiving. Mothers receiving more social support reported less negative perceptions. Mothers who used emotional coping reported a greater level of negative perceptions, whereas those who used relationship coping reported a lower level of negative perceptions. Mothers who had higher family income had more positive perceptions and mothers of children with ASD had less positive perceptions. The amount of stress and level of support were not significantly related to positive care giving perceptions. However both problem focused and relationship focused coping were significantly related to positive perceptions. Emotion focused coping did not contribute significantly to positive perceptions.

Myers, Makintosh & Goin Kochel (2009)	493 parents (mostly mothers) of children with ASD, (mean age 8.6 years).	To investigate how autism has affected parents lives.	Web based questionnaire.	Content analysis revealed the following themes- 1) 71% reported stress. 2) Child's behaviour and demands of care and therapy; under which there were 4 negative themes i) difficulty dealing with behaviour ii) time demands of care and therapies iii) sleep problems/ exhaustion iii) struggles with schools and services and 2 Positive themes i) new understanding regarding disabilities, ii) glad for autism, uniqueness, would not change it. 3) Impact on parents personal well being, work lives and marital relationships. Under which there were 3 negative themes, i) marital/couple strain, ii) difficult emotions e.g. grief, depression, guilt, blame, iii) mother or fathers career/ employment affected, and 5 positive themes i) enriched lives, ii) positive emotions, compassion, joy, tolerance, patience, iii) learned to appreciate small things and slow down iii) spiritual life enriched iii) marriage enriched. 4) Impact on the family as a whole, including siblings and extended family. Under which were 4 negative themes i) effects on siblings ii) financial strain, iii) centre of their lives and iii) strained relationships with extended family members, and 2 positive themes were counterpart to these with other families saying positive things about family adjustment and on the siblings. Theme 5) Social isolation, i) restrictions on where we can go and what we can do, ii) loss of friends, no social life iii) bad treatment by strangers.
Olsson & Hwang (2008)	Families of 62 children (mothers, n=62 mothers, fathers n=49) with ID and a comparison group of parents of TD children (mothers n= 183 mothers, fathers n=141).	Explores whether wellbeing and positive perceptions in parents of children with ID are affected by socioeconomic disadvantage, household composition and parental characteristics and identifies whether protective factors explains variation more than the risk factors.	<ul style="list-style-type: none"> - Beck Depression Inventory (Beck & Steer 1996) with three positive alternatives added to each of the 21 items (Chow & Brenton 2001). - Socioeconomic status (adapted after Emerson et al., 2006). - Family Impact Questionnaire (FIQ) (Donenberg & Baker 1993). - Orientation to life questionnaire' (Antonovsky, 1991). - Satisfaction with level of participation in work, leisure and social activities was measured by 3 questions on likert scales. 	Most parents scored within the high well being group from the BDI scores. Mothers of children with ID had more health problems, mothers and fathers of children with ID scored higher on the hardship scales compared with control mothers. Overall mothers scored higher on hardship. ID status did not make a significant contribution to variance, however the greater the economic hardship the lower the wellbeing and high scores on health correlated significantly with higher well being. Protective factors (parental personality characteristics (SOC), perceived positive impact and satisfaction with life) accounted for variance better for mothers than it did for fathers (78% and 42%). For mothers all predictors apart from hardship made a contribution, with SOC and positive perceptions been the strongest predictor of well being. For fathers only self-rated health made a strong contribution to the model.
Paczowski & Baker (2008)	Participants were 167 families of children with ID but not ASD, (n=72) or TD (n=95). Assessed at 3, 5 and 7yrs.	Examines how mothers' positive beliefs in fluence the relationship between children's CB and mothers' parenting stress.	<ul style="list-style-type: none"> - Demographic information. - Bayley Scales of Infant Development (Bayley, 1993). - A self mastery scale (Pearlin & Schooler, 1978). - Life orientation test revised (LOT- R, Scheier et al 1994). - Family Impact Questionnaire, (FIQ, Donenberg & Baker, 1993). - Child Behaviour Checklist (CBCL, Achenbach & Rescoria, 2001). 	Mothers of children with ID at age 3 reported less positive beliefs that mothers of typically developing children at age 3. The mothers of children with ID reported higher levels of CB than the TD group at ages 3, 5 and 7yrs. Mothers who reported higher levels of CB also reported higher levels of stress in the TD and ID group at ages 3, 5 and 7yrs with. CB do however increase over time whereas stress does not. Higher levels of positive belief was significantly associated with lower parenting stress among mothers in the ID group at all ages and for the TD group at age 3. This relationship was mediated by higher levels of psychological resources i.e. self-mastery and optimism. Mothers of TD children with high levels of positive beliefs whose children were low in CB, reported the lowest levels of parenting stress, whereas mothers whose children had ID who reported low levels of positive beliefs and whose children were high in CB reported the highest levels of stress. Positive beliefs were found to have a main effect relation to parenting stress above and beyond the effect of CB for the TD group and ID group at age 3yrs and for the TD group at age 7yrs. There was support for a mediation model where positive beliefs affect parenting stress via their relation to behavioural problems in the DD group at ages 3, 5 and 7yrs and in the TD group at age 3. In addition, in the DD group, higher positive beliefs at age 3yrs predicted lower parenting stress at age 7yrs and this effect was fully mediated by children's behaviour problems assessed at age 5yrs.

Taunt & Hastings (2002)	Two samples. Sample 1 was 14 parents (fathers n=4, mothers, n=10) of 10 families with a child with an ID and 2 siblings also participated (20yr old male and 16yr old female). Sample 2 was 33 (mothers, n=23, fathers n=10) parents. The sample were parents to a total of 40 children with ID (n=19 male, n=15 female, age range 1-24yrs).	Study looked at parents' perceptions of positive effects on siblings and on the extended family and whether parents report positive views about the future in addition to positive effects in the present and in the past. Looks at the child's positive impact on the parent.	Content analysis on semi structured interview and questionnaire.	Sample 1 themes for positive impact on families consists of- 1) positive aspects of child 2) changed perspective on life, 3) increased sensitivity, 4) support from other families, 5) opportunities to learn, 6) improved family dynamics. Sample 1 positive impact on siblings and extended family 1) increased sensitivity, 2) positive effect on siblings 3) changed perspective on life, 4) improved extended family dynamics, 5) opportunities to learn Sample 2 categories for positive impact on families consist of- 1) changed perspective on life 2) increased sensitivity, 3) positive aspects of the child, 4) opportunities to learn, 5) opportunities to expand social network of make a difference 6) improved family dynamics, 7) increased confidence r assertiveness, 8) strengthened religious faith. Sample 2 positive impact on siblings and extended family 1) positive attitude towards others 2) improved extended family dynamics 3) opportunities to learn, 4) greater sense of responsibility (specific to siblings) Sample 1 and 2 perspective on the future 1) generally hopeful 2) generally fearful and anxious 3) expressed hopes and fears 4) not looking to the future.
Trute, Benzie, Worthington, Reddon & Moore (2010)	Mothers, n= 195 (mean age 37.6 yrs). Child diagnosis of ID, n=106, physical or motor impairments, n= 12, mental health disorders, n=36, sensory impairments, n= 5, complex health conditions, n=7 and unconfirmed, n= 6. Age range 1-18yrs.	The study aims to examine how mothers appraisals impact on family functioning when coping resources.	<ul style="list-style-type: none"> - Brief Family Assessment Measure III (FAM-BF, Skinner, Steinhauer & Santa-Barbara, 1995). - Family Impact of Childhood Disability (FICD) Scale, (Trute & Hiebert-Murphy, 2005). - Positive and Negative Affect Schedule (PANAS) (Watson, Clark, & Tellegen, 1988). 	Higher levels of family adjustment (were related to higher positive appraisal, family impacts of childhood disability and higher positive affect. Regression analysis indicated that positive and negative appraisal of childhood disability on the family contributed to the variance explained in family adjustment. Positive appraisal and positivity jointly explained 35% variance in family adjustment. Negative appraisal of family impact of childhood disability was no longer related to family adjustment when positivity was controlled for. The study suggests that negative appraisals may reflect limitations or challenges found by disability but it does not mean that the family becomes maladjusted, however the more positivity brought the higher overall adjustment

Trute, Hiebert-Murphy & Levine (2007)	103 families (mothers n=103 and fathers n=55) with children under 12yrs with ID.	Four questions, 1) are there gender differences in appraisals of the impact of disability, self esteem and family functioning at 6 and 18 months after entering disability services? 2) Is there stability over time? 3) Does appraisal at time 1 (T1) predict changes in parental self-esteem at time 2 (T2)? 4) Do cognitive coping resources predict longer-term family adjustment for mothers and fathers?	<ul style="list-style-type: none"> - Family Impact of Childhood Disability Scale- FICD (Trute & Hiebert-Murphy 2002). - The Rosenberg Self-Esteem Scale (Rosenberg, 1965). - Family Assessment Measure III- Brief Form (FAM-BF; Skinner, Steinhauer & Santa-Barbara, 1983, 1995). 	Mothers reported more positive appraisal at T1, but there was no difference between fathers and mothers negative appraisals. At T2 mothers and fathers positive scores about family impact converge. The negative subscale on the FICD has no significant differences between mothers and fathers at T1 or T2. Gender differences were also found at T1 in the relationship between parent positive and negative appraisals of the family impact of childhood disability. Fathers showed higher self-esteem at T1 and T2 however, mothers self esteem at both times were within normal ranges. Family well being-scores on the FAM-BF were significantly different at T1 with mothers reporting more positive levels of family functioning, the difference was no longer significant at T2 and mothers and fathers scores at both times on FAM-BF were within normal ranges. T-tests showed stability over time for all psychosocial measures. Father's scores on family wellbeing at T2 had declined significantly but were still within the normal clinical range at T1 and T2. Self-esteem scores were stable across T1 and T2 for mothers and fathers. For mothers, T2 self esteem was predicted by positive appraisal of the family impact of childhood disability. Negative appraisal of family impact was not related to change in level of parental self-esteem in mothers. For fathers, self-esteem at T2 was not predictive of positive or negative family impact. Childhood disability is identified in this study as a stressor and the effect of cognitive coping resources (i.e. self-esteem and parental cognitive appraisal of the impact of the stressor) was tested. For mothers cognitive coping resources at T1 accounted for 35% of the variance at T2 in family well being. Self-esteem scores and cognitive appraisal scores of the impact of the stressor (Positive and negative) were found to be significant predictors of family well being. For fathers, cognitive coping resources at T1 accounted for 25% of variance at T2. Self-esteem was found to be a significant predictor and perceived negative impact of
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Appendix 1.2: Quality review of qualitative articles included in the review based on Sale and Brazil's (2004) critical appraisal criteria.

+ = the paper has fulfilled indicated criteria, /= the criteria is not applicable to the study, a blank box indicates that the criteria has not been met

		Qualitative papers used in review							Mixed methods	
Qualitative Criteria Indicated under 4 categories		Altiere & Von Kluge (2009)	King et al (2005)	Taunt & Hastings (2002)	Myers et al (2009)	Bostrom et al (2009)	Corman (2009)		Green (2007)	Larson (2009)
Truth Value (Credibility versus Internal Validity)	Triangulation of sources	+	+	+	+	+	+		+	+
	Triangulation of methods			+	+		+		+	+
	Triangulation of investigators	+	+	+	+	+				
	Triangulation of theory	+	+	+	+		+			+
	Peer debriefing		+		+					
	Negative case analysis									
	Member checks	+	+							+
	Use of quotations	+	+		+	+	+		+	+
	Informed consent stated		+		+					
	Ethical review	+	+		+	+			+	+
	Statement of confidentiality				+					
	Consent described		+		+					+
	12	6	9	4	10	4	5		4	7
Applicability (Transferability versus external validity/ generalisability)	Statement of purpose	+	+	+	+	+	+		+	+
	Statement of research	+	+	+	+	+	+		+	+
	Rationale qualitative method	+	+	+	+	+	+			+
	Rationale qualitative tradition					+				
	Description of study context	+	+	+	+	+	+		+	+
	Statement of selecting context			+	+	+	+		+	+
	Statement of selection setting	+		+	+	+	+			+
	Sampling procedure	+	+	+	+	+	+		+	+
	Rationale sampling strategy		+	+		+	+		+	+
	Description of participants	+		+	+	+	+		+	+
	Data gathering described	+	+	+	+	+	+		+	+
	Audio taping described		+		/	+			/	+
	Transcription described		+		/	+	+		/	+
	Field note procedures described		+		/				/	

	Data analysis described		+	+	+	+	+			+
	Coding techniques described		+	+	+	+				+
	Collection to saturation specified			+			+			
	Reflexive journals kept									
	Description raw data		+	+	+	+				+
	19	8	14	14	12	16	13		8	15
Consistency(Dependability versus reliability)	External audit process		+	+	+					
	1	0	1	1	1	0	0		0	0
Neutrality (Conformability versus objectivity)	External audit of data and reconstruction		+	+	+	+				
	Bracketing			+	+	+				
	Statement of researchers assumptions/ perspective					+			+	
	3	0	1	2	2	3	0		1	0

Appendix 1.3: Quality review of quantitative articles included in the review based on Sale and Brazil's (2004) critical appraisal criteria.

+ = the paper has fulfilled indicated criteria, /= the criteria is not applicable to the study, a blank box indicates that the criteria has not been met

		Quantitative papers used in review																Mixed method	
Quantitative Criteria		Trute et al (2010)	Trute et al (2007)	Greer et al (2006)	Mak & Ho (2007)	Olsson & Hwang (2008)	Hastings et al (2002)	Al Yagon & Margalit (2009)	Hastings, Beck & Hill (2002)	Kayfitz, Gragg & Orr (2010)	Blacher & McIntyre (2006)	Griffith et al (2010)	Hastings et al (2005)	Packowski & Baker (2008)	Blacher & Baker (2007)	Ekas & Whitman (2010)	Bostrom et al (2010)	Green (2007)	Larson (2009)
Truth Value (Credibility versus Internal Validity)	Confounding variables identified	+	+	+	+	+		+	+	+	+	+	+	+	+	+	+	+	
	Differences controlled for in analysis	+	+	+	+	+		+		+	+	+	+	+	+	+	+		
	Statement of comparability of control to intervention	/	/	/	/	+	/	+	/	/	+	+	/	+	+	/	+	/	/
	Statement comp. group treated equally (int. aside)	/	/	/	/	+	/	+	/	/	+	+	/	+	+	/	+	/	/
	Informed consent stated		+							+	+					+	+		+
	Ethical review undertaken			+						+					+		+	+	+
	Statement of confidentiality						+			+							+		
		2	3	3	2	4	1	4	1	5	5	4	2	4	5	3	7	2	2
Applicability (Transferability versus external validity/ generalisability)	Statement of purpose	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
	Objective of study described	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
	Description of intervention	/	/	/	/	/	/	/	/	/	/	/	/	/	/	/	/	/	/
	Assessment of outcome blinded	/	/	/	/	/	/	/	/	/	/	/	/	/	/	/	/		/
	Description of setting/condition	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
	Design explicitly stated		+	+								+	+	+	+	+	+	+	
	Subject recruitment or sampling described	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
	Sample randomly selected																		
	Inclusion and exclusion criteria for participants stated explicitly	+	+	+	+	+		+			+	+	+	+		+	+		+
Study population defined		+	+	+	+	+	+	+	+	+	+	+	+	+		+	+	+	+

	Source of subjects stated	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
	Source of controls stated	/	/	/	/	+	/	+	/	/	+	+	/	+	+	/	+			/
	Control or comparison described	/	/	/	/	+	/	+	/	/	+	+	/	+	+	/	+			/
	Statement regarding non respondents	+	+	+		+	+			+						+	+		+	+
	Missing data addressed		+	+												+	+			
	Power calculation for sample size		+									+								
	Statistical procedure referenced/ described	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+		+	+
	Confidence intervals given for main results	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+			
	Data gathering procedure described	+	+	+		+	+	+	+	+	+	+	+	+	+	+	+		+	+
	Data collection instruments described	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+		+	+
	Hypotheses described	+					+	+	+	+		+	+	+	+	+				
	Statistical and clinical significance acknowledged	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+		+	+
	22	14	16	14	11	15	13	15	12	13	14	17	14	16	14	16	17		12	12
Consistency(Dependability versus reliability)	Standardisation of observers described	/	/	/	/	/	/	/	/	/	/	/	/	/	/	/	/		/	/
	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0

Appendix 2

Ethical Approval

Appendix 3

3.1: Letter

3.2: Information sheet for participants under 16

3.3: Information sheet for participants over 16

3.4: Personal Nominee Consultee Information Sheet

Appendix 3.1: Letter



UNIVERSITY OF
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«AddressBlock»

Date

Re: Name of participant

Dear Name of parent/carer/guardian,

You may remember that you and your **son/daughter (name)** have taken part in our research before by completing questionnaires about the person you care for. We hope you found the feedback that we sent to you helpful.

We are now continuing this project by carrying out a follow-up to find out about changes and progress since we first contacted you. This is the first study to follow people with an autistic spectrum disorder up over such a long period of time and the results of this study will be important for understanding how people with autism change as they grow older. The more people that take part in the research, then the more meaningful the results are. A good response at this follow up will provide new and valuable information.

We are contacting you because you have agreed for your personal details to be kept at the Cerebra Centre for Neurodevelopmental Disorders at the University of Birmingham, and to be contacted with information about future research at the centre. We would like to invite you and your **son/daughter (name)** to continue to take part in this research by completing the enclosed questionnaires. When we have analysed the information you send to us, we will provide personalised feedback about the person you care for and we will report any changes from previous assessments.

There is an information sheet enclosed that gives you more details about why the research is being carried out and what it will involve. If you and your child/person you care for would like to take part in the study then please complete the enclosed consent form and questionnaire pack and return them in the pre-paid envelope provided.

Please read the information sheets before completing the questionnaires and if you are unclear about any aspect of the study or have any questions then contact Professor Chris Oliver at the address below or on

Thank you for your time and we look forward to hearing from you.

Yours sincerely

Chris Oliver

Professor of Neurodevelopmental Disorders

Sarah Weaver

Trainee Clinical Psychologist

Appendix 3.2: Information sheet for participants under 16

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Understanding Behaviour in Individuals with Neurodevelopmental Disorders: Information Sheet

Please read this information carefully before deciding whether you wish to take part in the study. If you have any further questions please contact Professor Chris Oliver on [REDACTED] or at [REDACTED]. If you have any medical/ other problems which make it difficult for you to read this information, please contact Professor Chris Oliver for a verbal explanation of the research.

When you are happy that you have all of the information you need to be able to decide whether or not you and your child/the person you care for would like to take part in the study, please complete the enclosed consent form and questionnaire pack return them to us in the prepaid envelope provided

Background to the study:

You may remember that you have taken part in our research before by completing questionnaires about the person you care for. We hope you found the feedback that we sent to you helpful. We are now extending this project by carrying out a one year follow-up to find out about changes since we first contacted you. The results of this study will be important for understanding how people change as they grow older. Currently, very little is known about how people with Autistic Spectrum Disorder progress and change over time. The more people that take part in this research, then the more meaningful the results are. A good response at this one year follow up will provide new and valuable information concerning age related behaviour changes seen in Autistic Spectrum Disorder.

Aims of the study:

1. To further our understanding of challenging behaviour, repetitive behaviour, hyperactivity, mood and social functioning in individuals with Autistic Spectrum Disorder.
2. To understand what happens with regard to these behaviours as children and adults develop.
3. To understand what, if any, changes may occur with regard to these behaviours when the individuals reach a certain age.
4. To understand the impact of having a child with a disability has on the family.

What will happen if you and your child/the person you care for decide(s) to participate?

Where will the research take place?

The research will involve completing the enclosed questionnaire pack. This can be completed by you in your own time.

Who will be involved in collecting the data?

Members of the research team at the Cerebra Centre for Neurodevelopmental disorders including disorders including Professor Chris Oliver and Dr. Joanna Moss and Sarah Weaver.

How long will participation in the study take?

The questionnaire pack will take approximately 45 minutes to complete.

In the future you may be asked if you would like to complete the questionnaire again so that we can start to understand what happens to people with Autistic Spectrum Disorder across their lifetime. We will only contact you with this invitation if you have previously agreed to be contacted by the research team at the University of Birmingham with information about research studies conducted by the team.

Sometimes after you have completed the questionnaire, we may need to contact you again in order to clarify any information that you have provided or to ask you for further information regarding the diagnosis of the person you care for. This helps us to ensure that our data is as useful and as accurate as possible. If this happens then we would contact you again within 6 months of receiving your questionnaire pack to ask whether or not you would be willing to provide us with the extra information.

What will participants be required to do during the study?

We will ask parents and caregivers to complete the enclosed questionnaire pack and return it to us alongside the consent form in the pre-paid envelope provided.

Are there any risks that individuals taking part in the study might face?

There will not be any risks associated with participation in this study.

What are the potential benefits for participants from taking part?

You will receive a personalised feedback regarding your child/ the person you care for. This study will help us to find out more about the lives of people with Autistic Spectrum Disorder and the difficulties that these people face. The results might help us to improve things for people with Autistic Spectrum Disorder in the future. You will have the option to decide whether or not you would be happy to be contacted by the University of Birmingham on behalf of Great Ormond Street Hospital for a full clinical/medical evaluation by the clinical genetics team should this be considered appropriate. This is optional and will not affect your participation in the current study. Unfortunately it will not be possible for everyone who participates in the study to be invited for this clinical evaluation.

Where will data be stored?

The data collected will be kept in locked or password protected storage at the University of Birmingham. Only members of the research team at the University of Birmingham will have access to information that we collect about you. Information will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998.

If you/ the person you care for decide(s) to participate, what will happen after that participation?

You and your child or person you care for will receive an individual feedback report describing the results of all of the assessments that were carried out during the study. If requested by, this feedback report will be circulated to other interested individuals. Descriptions of research findings will be published in newsletters of the relevant family support groups and educational institutions involved. Any request for advice concerning the person you care for will be referred to Professor Chris Oliver, Clinical Psychologist.

The researchers will publish the findings from the study in scientific journals and will present the results at relevant conferences.

What will happen to the data afterwards?

The information that you provide will be locked in a filing cabinet at the University of Birmingham or held on a password protected database. Participants will be identified by a unique number so that the information you provide us with cannot be traced to your personal details. . You will be able to decide whether or not you want to make your research data available to any professionals or clinicians working with you and the person you care for should they wish to see it. This is optional and will not affect your participation in the current study. If you agree to this, then your research data will only be made available to relevant clinicians or professionals should they contact us directly and request to see it. If you do not agree to this then research data will not be made available to anyone other than the research team at the University of Birmingham.

What will happen to my personal details afterwards?

Since you have previously been involved in our research projects at the University of Birmingham and have agreed to be contacted by the research team with information about future research work, we have a copy of your personal details on the 'Regular Participant Database'. This database is password protected and only approved members of our research team have access to your details. We do not share your details with anyone outside the research team.

What happens if I decide that I no longer want my details on the Regular Participant Database?

All you would need to do is contact Chris Oliver on [REDACTED] or at [REDACTED] or at the School of Psychology, University of Birmingham, Edgbaston, Birmingham, B15 2TT. Your details would be removed from the database immediately.

Consent

After having read all of the information and having received appropriate responses to any questions that you may have about the study you will be asked to give your and your child's/ person you care for consent to participate in the study if you decide that you do wish to participate. The section below on 'Giving consent' will explain this process. We need to receive consent from/ on behalf of potential participants in order for them to participate.

Withdrawal

Even after consent has been granted, participants can request to be withdrawn from the study at any time, without giving a reason. Even after participation has taken place, consent can be withdrawn and any data collected will be destroyed. This will not restrict

the access of you/ the person you care for to other services and will not affect their right to treatment.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. Please contact Chris Oliver on [REDACTED] or at [REDACTED] in the first instance. If you remain unhappy and wish to complain formally, you can contact: Professor Chris Miall; Head of School; School of Psychology, University of Birmingham, Birmingham, B15 2TT, by email: [REDACTED] or by phone on [REDACTED]

Confidentiality

The confidentiality of participants will be ensured. If published, information on the participant will be presented without reference to their name or any other identifying information. All personal details will be kept separately from the information collected so that it will only be possible to connect results to individuals via a special code. This will ensure that results are kept anonymous. In the unlikely event of any evidence of abuse being identified, this information will be disclosed by the research workers.

Review

The study has been approved by [REDACTED] Research Ethics Committee. For any queries or concerns regarding the ethical approval of this study please contact [REDACTED] on [REDACTED] quoting study reference number: [REDACTED]

Further information

If you would like any more information about the study please contact Professor Chris Oliver on [REDACTED] or at [REDACTED]. Or write to Chris Oliver, School of Psychology, University of Birmingham, Edgbaston, Birmingham, B15 2TT.

Giving consent

Now it is up to you whether you decide that you and your child/the person you care for would like to participate. The decision about whether or not to take part in the study must be 'informed'. This means that anyone making the decision must understand exactly what is involved in the study, what will be required from participants and why.

IMPORTANT:

You need to decide whether your child/the person you care for is able to understand enough about the study to make an 'informed' decision independently about whether or not they would like to participate and to communicate this decision to you. If you are unsure whether or not your child/person you care for is able to understand enough to make a decision independently then we can provide you with some guidelines to help you to assess this. A symbol information sheet can also be made available to you if this would be of help.

Please contact Professor Chris Oliver [redacted] or [redacted] to request a copy of this.

Please choose from one of the following options:

- 1. My child/ the person I care for is able to understand what is involved in the study and what will be required from them if they participate and has communicated their decision to me:**

If you think that the person is is able to understand enough about the study in order to make an 'informed' decision and they decide that they would like to participate then please ensure that they complete **Section 1 of Consent Form A coloured YELLOW** enclosed. A parent/carer will need to complete **Section 2 of Consent From A coloured YELLOW** in order to indicate that they also agree to participate in the study. A symbol information sheet can be made available in order to support your child/person you care for in making this decision if it would be of help. Please contact the research team if you would like a copy of the symbol consent form or if you need us to adapt this information further in order to suit your child's needs. Please return the consent form along with the questionnaire pack to us in the prepaid envelope provided.

- 2. My child/ the person I care for is unable to understand what is involved in the study and what will be required from them if they participate (either because they are too young to understand or because they are unable to understand) and cannot communicate their decision to me:**

If you are reading this information on behalf of someone you care for who is under the age of 16 years and you decide that the person is not able to make an 'informed' and independent decision about whether or not they would like to participate, then we would like to ask you to decide whether or not you think that it is in your child's best interests for them to participate in the study and whether you would like to provide your consent to participation on their behalf. If you would like your child/person you care for to participate in this study, please complete **Consent Form B coloured PURPLE** enclosed. Please return the consent form along with the questionnaire pack to us in the prepaid envelope provided.

Appendix: 3.3: Information sheet for participants over 16

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Understanding Behaviour in Individuals with Neurodevelopmental Disorders: Information Sheet

Please read this information carefully before deciding whether you wish to take part in the study. If you have any further questions please contact Professor Chris Oliver on [REDACTED] or at [REDACTED]. If you have any medical/ other problems which make it difficult for you to read this information, please contact Professor Chris Oliver for a verbal explanation of the research.

When you are happy that you have all of the information you need to be able to decide whether or not you and your child/the person you care for would like to take part in the study, please complete the enclosed consent form and questionnaire pack return them to us in the prepaid envelope provided

Background to the study:

You may remember that you have taken part in our research before by completing questionnaires about the person you care for. We hope you found the feedback that we sent to you helpful. We are now extending this project by carrying out a one year follow-up to find out about changes since we first contacted you. The results of this study will be important for understanding how people change as they grow older. Currently, very little is known about how people with Autistic Spectrum Disorder progress and change over time. The more people that take part in this research, then the more meaningful the results are. A good response at this one year follow up will provide new and valuable information concerning age related behaviour changes seen in Autistic Spectrum Disorder.

Aims of the study:

5. To further our understanding of challenging behaviour, repetitive behaviour, hyperactivity, mood and social functioning in individuals with Autistic Spectrum Disorder.
6. To understand what happens with regard to these behaviours as children and adults develop.
7. To understand what, if any, changes may occur with regard to these behaviours when the individuals reach a certain age.
8. To understand the impact of having a child with a disability has on the family.

What will happen if you and your child/the person you care for decide(s) to participate?

Where will the research take place?

The research will involve completing the enclosed questionnaire pack. This can be completed by you in your own time.

Who will be involved in collecting the data?

Members of the research team at the Cerebra Centre for Neurodevelopmental disorders including disorders including Professor Chris Oliver, Dr. Joanna Moss and Sarah Weaver.

How long will participation in the study take?

The questionnaire pack will take approximately 45 minutes to complete.

In the future you may be asked if you would like to complete the questionnaire again so that we can start to understand what happens to people with Autistic Spectrum Disorder across their lifetime. We will only contact you with this invitation if you have previously agreed to be contacted by the research team at the University of Birmingham with information about research studies conducted by the team.

Sometimes after you have completed the questionnaire, we may need to contact you again in order to clarify any information that you have provided or to ask you for further information regarding the diagnosis of the person you care for. This helps us to ensure that our data is as useful and as accurate as possible. If this happens then we would contact you again within 6 months of receiving your questionnaire pack to ask whether or not you would be willing to provide us with the extra information.

What will participants be required to do during the study?

We will ask parents and caregivers to complete the enclosed questionnaire pack and return it to us alongside the consent form in the pre-paid envelope provided.

Are there any risks that individuals taking part in the study might face?

There will not be any risks associated with participation in this study.

What are the potential benefits for participants from taking part?

You will receive a personalised feedback regarding your child/ the person you care for. This study will help us to find out more about the lives of people with Autistic Spectrum Disorder and the difficulties that these people face. The results might help us to improve things for people with Autistic Spectrum Disorder in the future. You will have the option to decide whether or not you would be happy to be contacted by the University of Birmingham on behalf of Great Ormond Street Hospital for a full clinical/medical evaluation by the clinical genetics team should this be considered appropriate. This is optional and will not affect your participation in the current study. Unfortunately it will not be possible for everyone who participates in the study to be invited for this clinical evaluation.

Where will data be stored?

The data collected will be kept in locked or password protected storage at the University of Birmingham. Only members of the research team at the University of Birmingham will have access to information that we collect about you. Information will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998.

If you/ the person you care for decide(s) to participate, what will happen after that participation?

You and your child or person you care for will receive an individual feedback report describing the results of all of the assessments that were carried out during the study. If requested by, this feedback report will be circulated to other interested individuals. Descriptions of research findings will be published in newsletters of the relevant family support groups and educational institutions involved. Any request for advice concerning the person you care for will be referred to Professor Chris Oliver, Clinical Psychologist.

The researchers will publish the findings from the study in scientific journals and will present the results at relevant conferences.

What will happen to the data afterwards?

The information that you provide will be locked in a filing cabinet at the University of Birmingham or held on a password protected database. Participants will be identified by a unique number so that the information you provide us with cannot be traced to your personal details. You will be able to decide whether or not you want to make your research data available to any professionals or clinicians working with you and the person you care for should they wish to see it. This is optional and will not affect your participation in the current study. If you agree to this, then your research data will only be made available to relevant clinicians or professionals should they contact us directly and request to see it. If you do not agree to this then research data will not be made available to anyone other than the research team at the University of Birmingham.

What will happen to my personal details afterwards?

Since you have previously been involved in our research projects at the University of Birmingham and have agreed to be contacted by the research team with information about future research work, we have a copy of your personal details on the 'Regular Participant Database'. This database is password protected and only approved members of our research team have access to your details. We do not share your details with anyone outside the research team unless you tell us to.

What happens if I decide that I no longer want my details on the Regular Participant Database?

All you would need to do is contact Chris Oliver on [REDACTED] or at [REDACTED] or at the School of Psychology, University of Birmingham, Edgbaston, Birmingham, B15 2TT. Your details would be removed from the database immediately.

Consent

After having read all of the information and having received appropriate responses to any questions that you may have about the study you will be asked to give your and your child's/ person you care for's consent to participate in the study if you decide that you do wish to participate. The section below on 'Giving consent' will explain this process. We need to receive consent from/ on behalf of potential participants in order for them to participate.

Withdrawal

Even after consent has been granted, participants can request to be withdrawn from the study at any time, without giving a reason. Even after participation has taken place, consent can be withdrawn and any data collected will be destroyed. This will not restrict the access of you/ the person you care for to other services and will not affect their right to treatment.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. Please contact Chris Oliver on [redacted] or at [redacted] in the first instance. If you remain unhappy and wish to complain formally, you can contact: Professor Chris Miall; Head of School; School of Psychology, University of Birmingham, Birmingham, B15 2TT, by email: [redacted] or by phone on [redacted].

Confidentiality

The confidentiality of participants will be ensured. If published, information on the participant will be presented without reference to their name or any other identifying information. All personal details will be kept separately from the information collected so that it will only be possible to connect results to individuals via a special code. This will ensure that results are kept anonymous. In the unlikely event of any evidence of abuse being identified, this information will be disclosed by the research workers.

Review

The study has been approved by [redacted] Research Ethics Committee. For any queries or concerns regarding the ethical approval of this study please contact [redacted] on [redacted] quoting study reference number: [redacted].

Further information

If you would like any more information about the study please contact Professor Chris Oliver on [redacted] or at [redacted]. Or write to Chris Oliver, School of Psychology, University of Birmingham, Edgbaston, Birmingham, B15 2TT.

Giving consent

Now it is up to you whether you decide that you and your child/the person you care for would like to participate. The decision about whether or not to take part in the study must be 'informed'. This means that anyone making the decision must understand exactly what is involved in the study, what will be required from participants and why.

IMPORTANT:

You need to decide whether your child/the person you care for is able to understand enough about the study to make an 'informed' decision independently about whether or not they would like to participate and to communicate this decision to you. If you are unsure whether or not your child/person you care for is able to understand enough to make a decision independently then we can provide you with some guidelines to help you to assess this. A symbol information sheet can also be made available to you if this would be of help.

Please contact Professor Chris Oliver [redacted] or [redacted] to request a copy of this.

Please choose from one of the following options:

1. My child/ the person I care for is able to understand what is involved in the study and what will be required from them if they participate and has communicated their decision to me:

If you think that the person is is able to understand enough about the study in order to make an 'informed' decision and they decide that they would like to participate then please ensure that they complete **Section 1 of Consent Form A coloured YELLOW** enclosed, or that you complete it with them, on their behalf. A parent/carer will need to complete **Section 2 of Consent Form A coloured YELLOW** in order to indicate that they also agree to participate in the study. A symbol information sheet can be made available in order to support your child/person you care for in making this decision if it would be of help. Please contact the research team if you would like a copy of the symbol consent form or if you need us to adapt this information further in order to suit your child's needs. Please return the consent form along with the questionnaire pack to us in the prepaid envelope provided.

2. My child/ the person I care for is over the age of 16 and cannot understand what is involved in the study or cannot communicate their decision to me:

If you are reading this information on behalf of someone you care for who is over the age of 16 and you decide that the person is not able to make an 'informed' decision about whether or not they would like to participate, then we would like to invite you to act as a 'personal consultee' (or 'nominated consultee' where an unpaid carer e.g. parent, legal guardian etc is not able to act as a 'personal consultee') for that person. Please read the enclosed 'Personal and Nominated Consultee Information Sheet' coloured **PINK**. Once you have finished reading the 'Personal and Nominated Consultee Information Sheet' please decide whether or not you feel able to act as a personal or nominated consultee for the person you care for.

If you feel able to act as a personal or nominated consultee for the person you care for please think about whether the person would decide to participate if they were able to make an 'informed' decision themselves about whether or not to participate. If you decide that the person would decide to participate, please complete **Consent Form C coloured BLUE** enclosed and return it to us alongside the questionnaire pack in the prepaid envelope provided.

Appendix 3.4: Personal Nominee Consultee Information Sheet

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Personal and Nominated Consultee Information Sheet

Please read this information sheet if you care for a person who is over the age of 16 who you have judged *is not* able to make an 'informed' decision about whether or not they would like to take part in the study or *is not* able to communicate that decision to you.

If you are an unpaid carer (e.g. parent, legal guardian etc) we would like to invite you to act as a **personal consultee** for the person that you care for. If you are a paid carer (e.g. paid carer, key worker, support worker etc) and there are no unpaid carers (e.g. parent, legal guardian etc) to act as a personal consultee for the person you care for then we would like to invite you to act as a **nominated consultee (go to page 3)**.

Information for Personal Consultees

What is a Personal Consultee?

In order to understand illness and disability, and to improve treatment and care, research is essential. That research may focus on the people with the illness or disability or on children over the age of 16, and may invite those people to participate. Some people will have capacity to make their own decision whether to take part in the research.

Others, possibly the youngest children or those most affected by the illness or disability, may not have that capacity. They may not be able to understand enough of the research to be able to give 'informed consent'. They may not be able to communicate a decision. The research provisions of the Mental Capacity Act are designed to allow such people to take part in research even though they cannot give valid consent of their own.

First, the research has to be approved by a Research Ethics Committee. Then, instead of asking the research participant for consent, the researcher must ask a consultee for an opinion whether the research participant would have wished to take part in the research.

Who can be a personal consultee?

Any person interested in the welfare of the proposed participant, for example:

- A family member, unpaid carer or friend
- A person acting under a Lasting Power of Attorney
- A court appointed deputy

Who cannot be a personal consultee?

- Paid carers and professionals (if you are a paid carer or professional please refer to **page 3**)
- People connected with the research (e.g. members of the research team)

Why have I been asked?

You have been asked to act as a personal consultee by a researcher because the researcher thinks you might be willing and able to do this because of your close relation with the proposed research participant.

If I agree to be a personal consultee, what will I have to do?

You will need to think about what the proposed participant's wishes and feelings about the research would be if they had capacity to make an informed decision and decide whether in your view the person should be involved in the research or not. This means you need to

- Look at the study information sheet.
- Think about whether or not the person would want to be involved in the research project if he or she had the capacity to make that decision.

You should not put forward your personal views on participation in the specific project or research in general, you must consider only what the person's views and interests are or would likely be. You should think about:

- What the broad aims of the research and the practicalities of taking part will mean for the proposed participant.
- How the specific activities in the research might impact the participant. For example, if the study involves activities in the afternoon when the person is most tired they might find it a strain or the research might involve an activity that the person particularly enjoys and thus would give them more pleasure.
- Any view previously expressed by the person on the overall nature of the research.

If you advise that the proposed participant would not have wanted to be involved in the research, they cannot be included in the research.

If you advise that the proposed participant would want to be involved, they may be included in the research. If the research commences but the person shows any sign at any stage that they are not happy to be involved in the research you can change your advice at any time without giving a reason, whereby the researcher must withdraw the person from the research. If the person seems unhappy at any point or shows any signs of objection, then they will be withdrawn from the research.

The research project has been approved by the [REDACTED] Research Ethics Committee. If you wish to see proof of approval from this body, or you wish to discuss any concerns about acting as a personal consultee for the person that you care for, please contact Chris Oliver on [REDACTED] or by email at [REDACTED]

I don't want to be a personal consultee/ I am a paid carer and so cannot be a personal consultee- what do I do?

Please try to suggest an alternative person who might like to act as a personal consultee for the potential participant, please pass the project information pack on to that person.

Where can I get more information and guidance?

More information is available from:

Department for Constitutional Affairs (2007) *Mental Capacity Act 2005 Code of Practice*
<http://www.dca.gov.uk/legal-policy/mental-capacity/mca-cp.pdf>

Department of Health (2007) *Guidance on nominating a consultee for research involving adults who lack capacity to consent* (consultation)
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_076207

Mental Capacity Implementation Programme (2007) *Making Decisions: a guide for family, friends and unpaid carers. Second edition*

<http://www.dca.gov.uk/legal-policy/mental-capacity/mibooklets/booklet02.pdf>

A printed copy of this booklet is available by telephoning 023 80878038.

I have decided that I want to be a personal consultee- what do I do?

Please go back to the 'understanding behaviour in neurodevelopmental disorders' Information Sheet and continue reading.

Information for Nominated Consultees

What is a Nominated Consultee?

In order to understand illness and disability, and to improve treatment and care, research is essential. That research may focus on the people with the illness or disability or on children under the age of 16, and may invite those people to participate. Some people will have capacity to make their own decision whether to take part in the research.

Others, possibly the youngest children or those most affected by the illness or disability, may not have that capacity. They may not be able to understand enough of the research to be able to give 'informed consent'. They may not be able to communicate a decision. The research provisions of the Mental Capacity Act are designed to allow such people to take part in research even though they cannot give valid consent of their own.

First, the research has to be approved by a Research Ethics Committee. Then, instead of asking the research participant for consent, the researcher must ask a consultee for an opinion whether the research participant would have wished to take part in the research.

Who can be a nominated consultee?

- Any person interested in the welfare of the proposed participant who works with the participant in a professional capacity.

Who cannot be a nominated consultee?

- People connected with the research (e.g. members of the research team)

Why have I been asked?

You have been asked to act as a nominated consultee by a researcher because the researcher thinks you might be willing and able to do this because of your professional relationship with the proposed research participant.

If I agree to be a nominated consultee, what will I have to do?

You will need to think about what the proposed participant's wishes and feelings about the research would be if they had capacity to make an informed decision and decide whether in your view the person should be involved in the research or not. This means you need to

- Look at the study information sheet.
- Think about whether or not the person would want to be involved in the research project if he or she had the capacity to make that decision.
- You may need to seek the advice of friends/ family/ other paid carers of the person you care for in order for you to best advise us on what the person's wishes and feelings would be.

You should not put forward your personal views on participation in the specific project or research in general, you must consider only what the person's views and interests are or would likely be. You should think about:

- What the broad aims of the research and the practicalities of taking part will mean for the proposed participant.
- How the specific activities in the research might impact the participant. For example, if the study involves activities in the afternoon when the person is most tired they might find it a strain or the research might involve an activity that the person particularly enjoys and thus would give them more pleasure.
- Any view previously expressed by the person on the overall nature of the research.

If you advise that the proposed participant would not have wanted to be involved in the research, they cannot be included in the research.

If you advise that the proposed participant would want to be involved, they may be included in the research. If the research commences but the person shows any sign at any stage that they are not happy to be involved in the research you can change your advice at any time without giving a reason, whereby the researcher must withdraw the person from the research. If the person seems unhappy at any point or shows any signs of objection, then they will be withdrawn from the research.

The research project has been approved by the [REDACTED] Research Ethics Committee. If you wish to see proof of approval from this body, or you wish to discuss any concerns about acting as a personal consultee for the person that you care for, please contact Professor Chris Oliver on ([REDACTED]) or at [REDACTED]

I don't want to be a nominated consultee - what do I do?

Please try to suggest an alternative person who might like to act as a nominated consultee for the potential participant, please pass the project information pack on to that person.

If no-one can be found who is willing and able to act as a consultee for the person you care for then the person will not be able to participate in the research study.

Where can I get more information and guidance?

More information is available from:

Department for Constitutional Affairs (2007) *Mental Capacity Act 2005 Code of Practice*
<http://www.dca.gov.uk/legal-policy/mental-capacity/mca-cp.pdf>

Department of Health (2007) *Guidance on nominating a consultee for research involving adults who lack capacity to consent* (consultation)
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_076207

Mental Capacity Implementation Programme (2007) *Making Decisions: a guide for family, friends and unpaid carers. Second edition*
<http://www.dca.gov.uk/legal-policy/mental-capacity/mibooklets/booklet02.pdf>

A printed copy of this booklet is available by telephoning 023 80878038.

I have decided that I want to be a nominated consultee- what do I do?

Please go back to the 'understanding behaviour in neurodevelopmental disorders' Information Sheet and continue reading.

Appendix 4

Consent Forms

4.1: For individuals who are able to provide consent to participate in the study

4.2: For children under the age of 16 who are not able to provide consent

4.3: For individuals over the age of 16 who are not able to provide consent

Appendix 4.1: For individuals who are able to provide consent to participate in the study

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Consent Form A : For individuals who are able to provide consent to participate in the study

Understanding behaviour and family adjustment in individuals with neurodevelopmental disorders

Study Director: Professor Chris Oliver

SECTION 1: Please complete this section if you are a person with Autistic Spectrum Disorder:

1. Has somebody else explained the project to you or have you read the information?

YES/NO

2. Do you understand what the project is about?

YES/NO

3. Have you asked all of the questions you want?

YES/NO

4. Have you had your questions answered in a way you understand?

YES/NO

5. Do you understand it is OK to stop taking part at any time?

YES/NO

6. Are you happy to take part?

YES/NO

If any answers are 'no' or you don't want to take part, don't sign your name!

If you do want to take part, you can write your name below

You can also choose if you want to say 'yes' to these questions:

7. If your Dr asks to see your results from this project is that OK?

YES/NO

8. Are you happy for us to contact you again in the future?

YES/NO

Your

name: _____

Date: _____

The person who explained this project to you needs to sign too. If you are under the age of 16 years, this should be your parent/guardian.

Print name: _____

Sign: _____

Date: _____

SECTION 2: Please complete this section if you are a parent/carer/guardian of a person with Autistic Spectrum Disorder who has provided their consent to participate in the study.

Please initial box...

1. I confirm that I have read and understood the information sheet dated February 2010 (V2 01.02.2010) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

☐

2. I understand that my participation and that of my child/person I care for is voluntary and that I am free to withdraw at any time without giving any reason, without my or that of my child's/person I care for's medical care or legal rights being affected.

☐

3. I understand that relevant sections of my child's/person I care for's GP medical notes regarding genetic diagnosis and health status may be looked at by members of the Cerebra Centre for Neurodevelopmental Disorders research team at the University of Birmingham, where it is

☐

relevant to this research project. I give permission for these individuals to have access to these records. ☐

4. I agree to my child's/person I care for's GP being informed of my participation and that of my child/person I care for's in the study, where access to my child's/person I care for's medical records is required. ☐

5. I agree to take part in the above study. ☐

Optional clauses: The two statements below are optional:

1. I agree to be contacted by the University of Birmingham on behalf of Great Ormond Street Hospital with an invitation for my child/person I care for to attend a clinical evaluation by the Great Ormond Street Hospital Clinical Genetics team should this be appropriate. ☐

2. I agree to the University of Birmingham research team sharing my research data with any professionals or clinicians working with me and the person I care for should they request to see them. ☐

Print Name: _____ Telephone number: _____

Address:

Relationship to participant: _____ Signature: _____ Date: _____

Appendix 4.2: For children under the age of 16 who are not able to provide consent

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Consent Form B: For children under the age of 16 who are not able to provide consent.

Understanding behaviour and family adjustment in individuals with neurodevelopmental disorders

Study Director: Professor Chris Oliver

Please complete this section if you are a parent/ guardian of a child (under 16 years) with Autistic Spectrum Disorder who is not able to provide consent.

Please initial box...

1. I confirm that I have read and understood the information sheet dated February 2010, (V2 01.02.2010) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation and that of my child/person I care for is voluntary and that I am free to withdraw at any time without giving any reason, without my or that of my child's/person I care for's medical care or legal rights being affected. ☐
3. I understand that relevant sections of my child's/person I care for's GP medical notes regarding genetic diagnosis and health status may be looked at by members of the Cerebra Centre for Neurodevelopmental Disorders research team at the University of Birmingham, where it is relevant to this research project. I give permission for these individuals to have access to these records. ☐
4. I agree to my child's/person I care for's GP being informed of my participation and that of my child/person I care for's in the study, where access to my child's/person I care for's medical records is required. ☐

5. I agree to take part in the above study.

☐

Optional clauses: The two statements below are optional:

3. I agree to be contacted by the University of Birmingham on behalf of Great Ormond Street Hospital with an invitation for my child/person I care for to attend a clinical evaluation by the Great Ormond Street Hospital Clinical Genetics team should this be appropriate.

☐

4. I agree to the University of Birmingham research team sharing my research data with any professionals or clinicians working with me and the person I care for should they request to see them.

☐

Print Name: _____ Telephone
number: _____

Address: _____

Relationship to participant: _____ Signature: _____ Date:

Appendix 4.3: For individuals over the age of 16 who are not able to provide consent

UNIVERSITY OF
BIRMINGHAM



Consent Form C: For individuals over the age of 16 who are not able to provide consent.

Understanding behaviour and family adjustment in individuals with neurodevelopmental disorders

Study Director: Professor Chris Oliver

Please read the following statements:

Please initial box...

1. I (your name)_____ have been consulted about (name of participant)_____’s participation in the above research project. I have had the opportunity to ask questions about the study and understand what is involved. ☐
2. In my opinion he/she would have no objection to taking part in the above study. ☐
3. I understand that I can request he/she is withdrawn from the study at any time without giving any reason and without his/her care or legal rights being affected. ☐
4. I understand that relevant sections of his/her GP medical notes regarding genetic diagnosis and health status may be looked at by members of the Cerebra Centre for Neurodevelopmental Disorders research team at the University of Birmingham, where it is relevant to this research project. I give permission for these individuals to have access to these records. ☐
5. I agree to his/herGP being informed of their participation in the study, where access to medical records is required. ☐

6. I agree to take part in the above study.

☐

Optional clauses: The two statements below are optional:

5. I agree to be contacted by the University of Birmingham on behalf of Great Ormond Street Hospital with an invitation for him/her to attend a clinical evaluation by the Great Ormond Street Hospital Clinical Genetics team should this be appropriate.

☐

6. I agree to the University of Birmingham research team sharing his/her research data with any professionals or clinicians working with them should they request to see them.

☐

Print Name: _____ Telephone
number: _____

Address: _____

Relationship to participant _____ Signature: _____ Date: _____

Appendix 5

Questionnaire Pack of Questionnaires used in the Study

- 5.1: Demographic Questionnaire**
- 5.2: Wessex Questionnaire**
- 5.3: Social Communication Questionnaire**
- 5.4: Activity Questionnaire Appendix**
- 5.5: Mood Pleasure and Interest Questionnaire**
- 5.6: The Challenging Behaviour Questionnaire**
- 5.7: The Shortened Questionnaire on Resources and Stress Form**
- 5.8: The Repetitive Behaviour Questionnaire**

Appendix 5.1: Demographic Questionnaire

ID _____																																
BACKGROUND INFORMATION																																
<p>Please tick or write your response to these questions concerning background details: Please answer the following about the <u>person you care for</u>:</p>																																
<p>1. Today's date: _____</p> <p>2. Gender: Male <input type="checkbox"/> Female <input type="checkbox"/></p> <p>3. Date of Birth: ____/____/____ Age: _____</p> <p>4. Is the person you care for verbal? (i.e. more than 30 signs/words in their vocabulary) Yes/No (delete as appropriate)</p> <p>5. Is the person you care for able to walk unaided? Yes/No (delete as appropriate)</p> <p>6. Has the person you care for been diagnosed with a syndrome? Yes/No (delete as appropriate) <i>If yes, please indicate which syndrome in 5a. and answer questions 6 to 8. If no, please move on to question 9</i></p> <table style="width: 100%; border: none;"> <tr> <td style="width: 40%;">6.a</td> <td style="width: 30%;">Autism <input type="checkbox"/></td> <td style="width: 30%;">High Functioning Autism <input type="checkbox"/></td> <td style="width: 10%;"></td> </tr> <tr> <td></td> <td>Asperger Syndrome <input type="checkbox"/></td> <td>Autistic like traits <input type="checkbox"/></td> <td></td> </tr> <tr> <td></td> <td>Autistic Spectrum <input type="checkbox"/></td> <td>Pervasive Development Disorder <input type="checkbox"/></td> <td></td> </tr> <tr> <td></td> <td>Autistic Continuum <input type="checkbox"/></td> <td></td> <td></td> </tr> <tr> <td></td> <td>Atypical Autism <input type="checkbox"/></td> <td></td> <td></td> </tr> <tr> <td></td> <td>Autism Spectrum Disorder <input type="checkbox"/></td> <td></td> <td></td> </tr> <tr> <td></td> <td>Other _____ <input type="checkbox"/></td> <td></td> <td></td> </tr> </table> <p>7. When was the person you care for diagnosed? _____</p> <p>8. Who diagnosed the person you care for?</p> <table style="width: 100%; border: none;"> <tr> <td style="width: 40%;">Paediatrician <input type="checkbox"/></td> <td style="width: 60%;">Clinical Geneticist <input type="checkbox"/></td> </tr> <tr> <td>GP <input type="checkbox"/></td> <td>Other _____ <input type="checkbox"/></td> </tr> </table> <p>9. Has the person you care for had any medical/health difficulties in the last six months? If yes, please give details: _____</p> <p><i>In the information sheet and consent form we informed you that we may need to contact your child's/person you care for's GP in order to clarify any information regarding your child's health and diagnostic status (see consent form and information sheet for more information). If you have already indicated on the consent form that you are happy for us to do this, please complete the relevant details below:</i></p> <p>10. Name of your child's/person you care for's GP _____</p> <p>GP _____</p> <p>Address _____</p> <p style="text-align: right;">GP Telephone _____</p> <p>number _____</p>	6.a	Autism <input type="checkbox"/>	High Functioning Autism <input type="checkbox"/>			Asperger Syndrome <input type="checkbox"/>	Autistic like traits <input type="checkbox"/>			Autistic Spectrum <input type="checkbox"/>	Pervasive Development Disorder <input type="checkbox"/>			Autistic Continuum <input type="checkbox"/>				Atypical Autism <input type="checkbox"/>				Autism Spectrum Disorder <input type="checkbox"/>				Other _____ <input type="checkbox"/>			Paediatrician <input type="checkbox"/>	Clinical Geneticist <input type="checkbox"/>	GP <input type="checkbox"/>	Other _____ <input type="checkbox"/>
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Paediatrician <input type="checkbox"/>	Clinical Geneticist <input type="checkbox"/>																															
GP <input type="checkbox"/>	Other _____ <input type="checkbox"/>																															

Appendix 5.1 ctd.

The following questions ask for background information <u>about you and your family</u>. Please tick the appropriate boxes or write in the spaces provided.																															
<p>1. Are you male or female? Male <input type="checkbox"/> Female <input type="checkbox"/></p> <p>2. What was your age in years on your last birthday? _____ years</p> <p>3. Please tick the highest level of your educational qualifications.</p> <table style="width: 100%; border: none;"> <tr> <td>No formal educational qualifications.....</td> <td style="text-align: right;"><input type="checkbox"/></td> </tr> <tr> <td>Fewer than 5 GCSE's or O Level's (grades A-C), NVQ 1, or BTEC First Diploma.....</td> <td style="text-align: right;"><input type="checkbox"/></td> </tr> <tr> <td>5 or more GCSE's or O Level's (grades A-C), NVQ 2, or equivalent.....</td> <td style="text-align: right;"><input type="checkbox"/></td> </tr> <tr> <td>3 or more 'A' Levels, NVQ 3, BTEC National, or equivalent.....</td> <td style="text-align: right;"><input type="checkbox"/></td> </tr> <tr> <td>Polytechnic/University degree, NVQ 4, or equivalent.....</td> <td style="text-align: right;"><input type="checkbox"/></td> </tr> <tr> <td>Masters/Doctoral degree, NVQ 5, or equivalent.....</td> <td style="text-align: right;"><input type="checkbox"/></td> </tr> </table> <p>4. What is your relationship to your child with a genetic syndrome (e.g. mother, father, stepmother, grandmother, adoptive parent)? _____</p> <p>5. In total how many people currently live in your home? _____ Adults _____ Children</p> <p>6. Does your child with a genetic syndrome normally live with you? Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p style="padding-left: 40px;">If no, then where do they live? _____</p> <p>7. What is your current marital status?</p> <table style="width: 100%; border: none;"> <tr> <td>Married, and living with spouse.....</td> <td style="text-align: right;"><input type="checkbox"/></td> </tr> <tr> <td>Living with partner.....</td> <td style="text-align: right;"><input type="checkbox"/></td> </tr> <tr> <td>Divorced/Separated/Widowed/Single and NOT living with a partner.....</td> <td style="text-align: right;"><input type="checkbox"/></td> </tr> </table> <p><i>If living with partner/spouse, please answer the following questions, if not, please go to question 12.</i></p> <p>8. Is your partner male or female? Male <input type="checkbox"/> Female <input type="checkbox"/></p> <p>9. What was their age in years on their last birthday? _____ years</p> <p>10. Please tick the highest level of your partner/spouse's educational qualifications.</p> <table style="width: 100%; border: none;"> <tr> <td>No formal educational qualifications.....</td> <td style="text-align: right;"><input type="checkbox"/></td> </tr> <tr> <td>Fewer than 5 GCSE or O Level (grades A-C), NVQ 1, or BTEC First Diploma.....</td> <td style="text-align: right;"><input type="checkbox"/></td> </tr> <tr> <td>5 or more GCSE or O Level (grades A-C), NVQ 2, or equivalent.....</td> <td style="text-align: right;"><input type="checkbox"/></td> </tr> <tr> <td>3 or more 'A' Levels, NVQ 3, BTEC National, or equivalent.....</td> <td style="text-align: right;"><input type="checkbox"/></td> </tr> <tr> <td>Polytechnic/University degree, NVQ 4, or equivalent.....</td> <td style="text-align: right;"><input type="checkbox"/></td> </tr> <tr> <td>Masters/Doctoral degree, NVQ 5, or equivalent.....</td> <td style="text-align: right;"><input type="checkbox"/></td> </tr> </table>		No formal educational qualifications.....	<input type="checkbox"/>	Fewer than 5 GCSE's or O Level's (grades A-C), NVQ 1, or BTEC First Diploma.....	<input type="checkbox"/>	5 or more GCSE's or O Level's (grades A-C), NVQ 2, or equivalent.....	<input type="checkbox"/>	3 or more 'A' Levels, NVQ 3, BTEC National, or equivalent.....	<input type="checkbox"/>	Polytechnic/University degree, NVQ 4, or equivalent.....	<input type="checkbox"/>	Masters/Doctoral degree, NVQ 5, or equivalent.....	<input type="checkbox"/>	Married, and living with spouse.....	<input type="checkbox"/>	Living with partner.....	<input type="checkbox"/>	Divorced/Separated/Widowed/Single and NOT living with a partner.....	<input type="checkbox"/>	No formal educational qualifications.....	<input type="checkbox"/>	Fewer than 5 GCSE or O Level (grades A-C), NVQ 1, or BTEC First Diploma.....	<input type="checkbox"/>	5 or more GCSE or O Level (grades A-C), NVQ 2, or equivalent.....	<input type="checkbox"/>	3 or more 'A' Levels, NVQ 3, BTEC National, or equivalent.....	<input type="checkbox"/>	Polytechnic/University degree, NVQ 4, or equivalent.....	<input type="checkbox"/>	Masters/Doctoral degree, NVQ 5, or equivalent.....	<input type="checkbox"/>
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Masters/Doctoral degree, NVQ 5, or equivalent.....	<input type="checkbox"/>																														

Appendix 5.1 ctd

11. What is your partner/spouse's relationship to your child with a genetic syndrome (e.g., mother, father, stepmother, adoptive parent)? _____

12. Recent data from research with families of children with special needs has shown that a family's financial resources are important in understanding family member's views and experiences. With this in mind, we would be very grateful if you could answer the additional question below. We are not interested in exactly what your family income is, but we would like to be able to look at whether those with high versus lower levels of financial resources have different experiences.

What is your current total annual family income? Please include a rough estimate of total salaries and other income (including benefits) before tax and national insurance/pensions.

Please tick one box only:

- | | |
|-------------------------|--------------------------|
| Less than £15,000..... | <input type="checkbox"/> |
| £15,001 to £25,000..... | <input type="checkbox"/> |
| £25,001 to £35,000..... | <input type="checkbox"/> |
| £35,001 to £45,000..... | <input type="checkbox"/> |
| £45,001 to £55,000..... | <input type="checkbox"/> |
| £55,001 to £65,000..... | <input type="checkbox"/> |
| £65,001 or more..... | <input type="checkbox"/> |

Please check your answers and go on to the next questionnaire.

Appendix 5.2: Wessex Questionnaire

WESSEX QUESTIONNAIRE				
<p>These items refer to the person you care for. For each question (A, B, C, D etc ...), please enter the appropriate code in each box.</p>				
A) <u>Wetting (nights)</u>	1 = frequently	2 = occasionally	3 = never	<input type="checkbox"/>
B) <u>Soiling (nights)</u>	1 = frequently	2 = occasionally	3 = never	<input type="checkbox"/>
C) <u>Wetting (days)</u>	1 = frequently	2 = occasionally	3 = never	<input type="checkbox"/>
D) <u>Soiling (days)</u>	1 = frequently	2 = occasionally	3 = never	<input type="checkbox"/>
E) <u>Walk with help*</u>	1 = not at all and elsewhere	2 = not up stairs	3 = up stairs	<input type="checkbox"/>
<p>*(note: if this person walks <i>by himself/herself</i> upstairs and elsewhere, please also code '3' for 'walk with help')</p>				
F) <u>Walk by himself</u>	1 = not at all	2 = not up stairs	3 = up stairs and elsewhere	<input type="checkbox"/>
G) <u>Feed himself</u>	1 = not at all	2 = with help	3 = without help	<input type="checkbox"/>
H) <u>Wash himself</u>	1 = not at all	2 = with help	3 = without help	<input type="checkbox"/>
I) <u>Dress himself</u>	1 = not at all	2 = with help	3 = without help	<input type="checkbox"/>
<p>J) <u>Vision</u> 1 = blind or almost 2 = poor 3 = normal <input style="float: right;" type="checkbox"/></p> <p>K) <u>Hearing</u> 1 = deaf or almost 2 = poor 3 = normal <input style="float: right;" type="checkbox"/></p> <p>L) <u>Speech</u> 1 = never a word 2 = odd words only <input style="float: right;" type="checkbox"/> 3 = sentences and normal 4 = can talk but doesn't</p>				
<p>If this person talks in sentences, is his/her speech:</p> <p>1 = Difficult to understand even by acquaintances, impossible for strangers?</p> <p>2 = Easily understood for acquaintances, difficult for strangers? <input style="float: right;" type="checkbox"/></p> <p>3 = Clear enough to be understood by anyone? <input style="float: right;" type="checkbox"/></p>				
M) <u>Reads</u>	1 = nothing	2 = a little	3 = newspapers and/or books	<input type="checkbox"/>
N) <u>Writes</u>	1 = nothing	2 = a little	3 = own correspondence	<input type="checkbox"/>
O) <u>Counts</u>	1 = nothing	2 = a little	3 = understands money values	<input type="checkbox"/>
<p>Please check your answers and go on to the next questionnaire.</p>				

Appendix 5.3: Social Communication Questionnaire

SOCIAL COMMUNICATION QUESTIONNAIRE		
Please circle 'yes' if <u>any</u> one of the following behaviours is present. Although you may be uncertain about whether some behaviours are present or not, please do answer 'yes' or 'no' to every question on the basis of what you think.		
1. Is she/he now able to talk using short phrases or sentences? If no, skip to question 8.	Yes	No
Do you have a to and fro "conversation" with her/him that involves taking turns or building on what you have said?	Yes	No
Does she/he ever use odd phrases or say the same thing over and over in almost exactly the same way (either phrases she/he has heard other people use or ones that she/he makes up)?	Yes	No
Does she/he ever use socially inappropriate questions or statements? For example, does she/he ever regularly ask personal questions or make personal comments at awkward times?	Yes	No
5. Does she/he ever get her/his pronouns mixed up (e.g. saying <i>you</i> or <i>she/he</i> instead of <i>I</i>)	Yes	No
Does she/he ever use words that she/he seems to have invented or made up her/himself; put things in odd, indirect ways; or use metaphorical ways of saying things (e.g. saying <i>hot rain</i> for <i>steam</i>)?	Yes	No
Does she/he ever say the same thing over and over in exactly the same way, or insist that you say the same thing over and over again?	Yes	No
Does she/he ever have things that she/he seems to have to do in a very particular way or order, or rituals that she/he insists that you go through?	Yes	No
9. Does her/his facial expression usually seem appropriate to the particular situation, so far as you can tell?	Yes	No
Does she/he ever use your hand like a tool, or as if it were part of her/his own body (e.g. pointing with your finger, putting your hand on a doorknob to get you to open the door)?	Yes	No
Does she/he ever have any interests that preoccupy her/him and might seem odd to other people (e.g. traffic lights, drainpipes or timetables)?	Yes	No
Does she/he ever seem to be more interested in parts of a toy or an object (e.g. spinning the wheels of a car), rather than using the object as it was intended?	Yes	No
Does she/he ever have any special interests that are <i>unusual</i> in their intensity but otherwise appropriate for her/his age and peer group (e.g. trains, or dinosaurs)?	Yes	No
14. Does she/he ever seem to be <i>unusually</i> interested in the sight, feel, sound, taste or smell of things or people?	Yes	No
Does she/he ever have any mannerisms or odd ways of moving her/his hands or fingers, such as flapping or moving her/his fingers in front of her/his eyes?	Yes	No
Does she/he ever have any complicated movements of her/his whole body, such as spinning or repeatedly bouncing up and down?	Yes	No
17. Does she/he ever injure her/himself deliberately, such as by biting her/his arm or banging her/his head?	Yes	No
18. Does she/he ever have any objects (<i>other</i> than a soft toy or comfort blanket) that she/he <i>has</i> to carry around?	Yes	No
19. Does she/he have any particular friends or a best friend?	Yes	No
20. Does she/he ever talk with you just to be friendly (rather than to get something)?	Yes	No
Does she/he ever spontaneously copy you (or other people) or what you are doing (such as vacuuming,		

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gardening or mending things)?	Yes	No
Does she/he ever spontaneously point at things around her/him just to show you things (not because she/he wants them)?	Yes	No
23. Does she/he ever use gestures, other than pointing or pulling your hand, to let you know what she/he wants?	Yes	No
24. Does she/he nod her/his head to indicate <i>yes</i> ?	Yes	No
25. Does she/he shake her/his head to indicate <i>no</i> ?	Yes	No
26. Does she/he usually look at you directly in the face when doing things with you or talking with you?	Yes	No
27. Does she/he smile back if someone smiles at her/him?	Yes	No
28. Does she/he ever show you things that interest her/him to engage your attention?	Yes	No
29. Does she/he ever offer to share things other than food with you?	Yes	No
30. Does she/he ever seem to want you to join in her/his enjoyment of something?	Yes	No
31. Does she/he ever try to comfort you if you are sad or hurt?	Yes	No
If she/he wants something or wants help, does she/he look at you and use gestures with sounds or words to get your attention?	Yes	No
33. Does she/he show a normal range of facial expressions?	Yes	No
Does she/he ever spontaneously join in and try to copy the actions in social games, such as The Mulberry Bush or London Bridge is Falling Down?	Yes	No
35. Does she/he play any pretend or make-believe games?	Yes	No
36. Does she/he seem interested in other children whom she/he does not know?	Yes	No
37. Does she/he respond positively when another child approaches her/him?	Yes	No
If you come into a room and start talking to her/him without calling her/his name, does she/he usually look up and pay attention to you?	Yes	No
Does she/he ever play imaginative games with another child in such a way that you can tell that each child understands what the other is pretending?	Yes	No
Does she/he play cooperatively in games that need some form of joining in with a group of other children, such as hide-and-seek or ball games?	Yes	No

Appendix 5.4: Activity Questionnaire

ACTIVITY QUESTIONNAIRE © C Burbidge and C Oliver (2003)					
Instructions: <ul style="list-style-type: none"> Please read each item carefully and circle the appropriate number on the scale, for the person you care for. Please ensure that you indicate a response for every item. If the particular behaviour does not apply, for example, if the person is not verbal or not mobile, please circle 0 on the scale. 					
	Never/ almost never	Some of the time	Half of the time	A lot of the time	Always/ almost all the time
1. Does the person wriggle or squirm about when seated or lying down?	0	1	2	3	4
2. Does the person fidget or play with their hands and/or feet when seated or lying down?	0	1	2	3	4
3. Does the person find it difficult holding still?	0	1	2	3	4
4. Does the person find it difficult to remain in their seat even when in situations where it would be expected?	0	1	2	3	4
5. Does the person prefer to be moving around or become frustrated if left in one position for too long?	0	1	2	3	4
6. When the person is involved in a leisure activity (e.g. watching TV, playing a game etc.) do they make a lot of noise?	0	1	2	3	4
7. When the person is involved in an activity, are they boisterous and/or rough?	0	1	2	3	4
8. Does the person act as if they are "driven by a motor" (i.e. often very active)?	0	1	2	3	4
9. Does the person seem like they need very little rest to recharge their battery?	0	1	2	3	4
10. Does the person often talk excessively?	0	1	2	3	4
11. Does the person's behaviour seem difficult to manage/contain whilst out and about (e.g. in town, in supermarkets etc.)?	0	1	2	3	4
12. Do you feel that you need to "keep an eye" on the person at all times?	0	1	2	3	4
13. Does the person you care for seem to act/do things without stopping to think first?	0	1	2	3	4
14. Does the person blurt out answers before questions have been completed?	0	1	2	3	4
15. Does the person start to respond to instructions before they have been fully given or without seeming to understand them?	0	1	2	3	4
16. Does the person want things immediately?	0	1	2	3	4
17. Does the person find it difficult to wait?	0	1	2	3	4
18. Does the person disturb others because they have difficulty waiting for things or waiting their turn?	0	1	2	3	4

Appendix 5.5: Mood Interest and Pleasure Questionnaire

MOOD, INTEREST AND PLEASURE QUESTIONNAIRE									
<p>This questionnaire contains 12 questions – you should complete all 12 questions. Each question will ask for your opinion about particular behaviours, which you have observed in the <u>LAST 2 WEEKS</u>. For every question you should circle <u>the most appropriate</u> response e.g.</p>									
<p>6) In the LAST TWO WEEKS, how interested did the person appear to be in his/her surroundings?</p> <table style="width: 100%; text-align: center;"> <tr> <td><i>interested all of the time</i></td> <td><i>interested most of the time</i></td> <td><i>interested about half of the time</i></td> <td><i>interested some of the time</i></td> <td><i>never interested</i></td> </tr> </table>					<i>interested all of the time</i>	<i>interested most of the time</i>	<i>interested about half of the time</i>	<i>interested some of the time</i>	<i>never interested</i>
<i>interested all of the time</i>	<i>interested most of the time</i>	<i>interested about half of the time</i>	<i>interested some of the time</i>	<i>never interested</i>					
<p>1) In the last two weeks, did the person seem...</p> <table style="width: 100%; text-align: center;"> <tr> <td>sad all of the time</td> <td>sad most of the time</td> <td>sad about half of the time</td> <td>sad some of the time</td> <td>never sad</td> </tr> </table> <p><i>Please comment if anything has happened in the last two weeks which you feel might explain sadness if it has been observed (e.g. a bereavement):</i></p>					sad all of the time	sad most of the time	sad about half of the time	sad some of the time	never sad
sad all of the time	sad most of the time	sad about half of the time	sad some of the time	never sad					
<p>2) In the last two weeks, how often did you hear positive vocalizations* when the person was engaged in activities*?</p> <table style="width: 100%; text-align: center;"> <tr> <td>all of the time</td> <td>most of the the time</td> <td>about half of the time</td> <td>some of the time</td> <td>never</td> </tr> </table> <p><small>*positive vocalizations: e.g. laughing, giggling, “excited sounds” etc. *engaged in activities: i.e. when someone is actively involved in any activity such as a mealtime, a social interaction, a self-care task or social outing etc.</small></p>					all of the time	most of the the time	about half of the time	some of the time	never
all of the time	most of the the time	about half of the time	some of the time	never					
<p>3) In the last two weeks, do you think the facial expression of the person looked “flat”*...</p> <table style="width: 100%; text-align: center;"> <tr> <td>all of the time</td> <td>most of the the time</td> <td>about half of the time</td> <td>some of the time</td> <td>never</td> </tr> </table> <p><small>*flat expression: expression seems lifeless; lacks emotional expression; seems unresponsive.</small></p>					all of the time	most of the the time	about half of the time	some of the time	never
all of the time	most of the the time	about half of the time	some of the time	never					
<p>4) In the last two weeks, would you say the person...</p> <table style="width: 100%; text-align: center;"> <tr> <td>cried every day</td> <td>cried nearly every day</td> <td>cried 3-4 times each week</td> <td>cried once or twice each week</td> <td>cried less than once each week</td> </tr> </table>					cried every day	cried nearly every day	cried 3-4 times each week	cried once or twice each week	cried less than once each week
cried every day	cried nearly every day	cried 3-4 times each week	cried once or twice each week	cried less than once each week					
<p>5) In the last two weeks, how interested did the person appear to be in his/her surroundings?</p> <table style="width: 100%; text-align: center;"> <tr> <td>interested all of the time</td> <td>interested most of the time</td> <td>interested about half of the time</td> <td>interested some of the time</td> <td>never interested</td> </tr> </table>					interested all of the time	interested most of the time	interested about half of the time	interested some of the time	never interested
interested all of the time	interested most of the time	interested about half of the time	interested some of the time	never interested					
<p>6) In the last two weeks, did the person seem to have been enjoying life...</p> <table style="width: 100%; text-align: center;"> <tr> <td>all of the time</td> <td>most of the the time</td> <td>about half of the time</td> <td>some of the time</td> <td>never</td> </tr> </table> <p><i>Please comment if there are any reasons why this person might not have been enjoying him/herself e.g. illness, being in pain, experiencing a loss etc.:</i></p>					all of the time	most of the the time	about half of the time	some of the time	never
all of the time	most of the the time	about half of the time	some of the time	never					
<p>7) In the last two weeks, would you say the person smiled...</p> <table style="width: 100%; text-align: center;"> <tr> <td>at least once every day</td> <td>at least once nearly every day</td> <td>3-4 times each week</td> <td>once or twice each week</td> <td>less than once each week</td> </tr> </table>					at least once every day	at least once nearly every day	3-4 times each week	once or twice each week	less than once each week
at least once every day	at least once nearly every day	3-4 times each week	once or twice each week	less than once each week					

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8) In the last two weeks, how disinterested did the person seem to be in his/her surroundings?

disinterested all of the time	disinterested most of the time	disinterested about half of the time	disinterested some of the time	never disinterested
----------------------------------	-----------------------------------	---	-----------------------------------	------------------------

9) In the last two weeks, when the person was engaged in activities*, to what extent did his/her facial expressions* suggest that s/he was interested in the activity?

interested all of the time	interested most of the time	interested about half of the time	interested some of the time	never interested
-------------------------------	--------------------------------	--------------------------------------	--------------------------------	---------------------

*engaged in activities: i.e. when someone is actively involved in any activity such as a mealtime, social interaction, self-care task or social outing etc.

*facial expressions: interest might be indicated by the degree to which the person's gaze is being directed at the person/things involved in an activity.

10) In the last two weeks, would you say that the person...

laughed every day	laughed nearly every day	laughed 3-4 times each week	laughed once or twice each week	laughed less than once each week
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11) In the last two weeks, how often did you see gestures which appeared to demonstrate enjoyment* when the person was engaged in activities*?

all of the time	most of the the time	about half of the time	some of the time	never
--------------------	-------------------------	---------------------------	---------------------	-------

*gestures which appear to demonstrate enjoyment: e.g. clapping, waving hands in excitement etc.

*engaged in activities: i.e. when someone is actively involved in any activity such as a meal time, social interaction, self-care task or social outing etc.

12) In the last two weeks, did the person's vocalizations* sound distressed...

all of the time	most of the the time	about half of the time	some of the time	never
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*vocalizations: any words, noises or utterances.

Please feel free to make any additional comments about the behaviour of the person over the last two weeks:

Appendix 5.6: The Challenging Behaviour Questionnaire

THE CBQ

1) Has the person shown self-injurious behaviour **IN THE LAST MONTH**? (e.g. head banging, head-punching or slapping, removing hair, self-scratching, body hitting, eye poking or pressing).

Yes ☐ No ☐

If the behaviour has not occurred, please go to question 6

If the behaviour occurred in the past month please answer all of the following questions:

2) Place a tick next to the item for any of the following list of behaviours which the person displays in a repetitive manner (repeats the same movement/behaviour twice or more in succession):

Hits self with body part (e.g. slaps head or face).....	<input type="checkbox"/>
Hits self against surface or object (e.g. bangs head on floor or table).....	<input type="checkbox"/>
Hits self with object.....	<input type="checkbox"/>
Bites self (e.g. bites hand or wrist or arm).....	<input type="checkbox"/>
Pulls (e.g. pulls hair or skin).....	<input type="checkbox"/>
Rubs or scratches self (e.g. rub marks on arm or leg).....	<input type="checkbox"/>
Inserts finger or objects (e.g. eye poking).....	<input type="checkbox"/>
Other form of self-injury, please specify:.....	<input type="checkbox"/>

3) In the last month, for how long did the longest episode or burst of his behaviour last? *(Please circle one number)*

1	2	3	4	5
Less than	Less than	Less than	Less than	More than
a minute	5 minutes	15 minutes	an hour	an hour

4) In the last month as a result of this behaviour, has physical contact or prevention or restraint by others been necessary e.g. blocking, taking objects from an individual, temporary restraint of an arm? *(Please circle one number)*

0	1	2	3	4
Never	At least once	At least once	At least once	At least once
	a month	a week	a day	an hour

5) Think about how often this behaviour occurred in the last month. If there was no change and you watched the person now, then would you definitely see the behaviour:

1	2	3	4	5
By this time	By this time	By this time	In the next	In the next
next month	next week	tomorrow	hour	15 minutes

6) Has the person shown physical aggression **in the last month**? (e.g. punching, pushing, kicking, pulling hair, grabbing other's clothing).

Yes ☐ No ☐

7) Has the person shown disruption and destruction of property or the environment **in the last month**? (e.g. tearing or chewing own clothing, tearing newspapers, breaking windows or furniture, slamming doors, spoiling a meal).

Yes ☐ No ☐

8) Has the person shown stereotyped behaviours **in the last month**? (e.g. rocking, twiddling objects, patting or tapping part of the body, constant hand movements, eye pressing).

Yes ☐ No ☐

Please check your answers and go on to the next questionnaire.

Appendix 5.7: The Shortened Questionnaire on Resources and Stress Form

PARENTING AND THE FAMILY		
1. Caring for _____ puts a strain on me	True	False
2. Other members of the family have to do without things because of _____	True	False
3. In the future, our family's social life will suffer because of the increased responsibilities and financial stress.	True	False
4. I can go to visit friends whenever I want	True	False
5. There are many places where we can enjoy ourselves as a family when ____ comes along	True	False
6. Members of our family get to do the same kinds of things other families do	True	False
7. The constant demands to care for _____ limit my growth and development	True	False

Appendix 5.8: The Repetitive Behaviour Questionnaire

THE RBQ © Moss & Oliver 2003

INSTRUCTIONS:

1. The questionnaire asks about 19 different behaviours.
2. Each behaviour is accompanied by a brief definition and examples. The examples given for each behaviour are not necessarily a complete list but may help you to understand the definitions more fully.
3. Please read the definitions and examples carefully and circle the appropriate number on the scale to indicate how frequently the person you care for has engaged in each of the behaviours WITHIN THE LAST MONTH.
4. If a particular behaviour does not apply to the person you care for because they are not mobile or verbal please circle the number 0 on the scale

	Never	Once a month	Once a week	Once a day	More than once a day
1. Object stereotypy: Repetitive, seemingly purposeless movement of objects in an unusual way <i>E.g. twirling or twiddling objects, twisting or shaking objects, banging or slapping objects.</i>	0	1	2	3	4
2. Body stereotypy: Repetitive, seemingly purposeless movement of whole body or part of body (other than hands) in an unusual way. <i>E.g. body rocking, or swaying or spinning, bouncing, head shaking, body posturing.</i> Does not include self-injurious behaviour.	0	1	2	3	4
3. Hand stereotypy: Repetitive, seemingly purposeless movement of hands in an unusual way. <i>E.g. finger twiddling, hand flapping, wiggling or flicking fingers, hand posturing.</i> Does not include self-injurious behaviour.	0	1	2	3	4
4. Cleaning: Excessive cleaning, washing or polishing of objects or parts of the body <i>E.g. polishes windows and surfaces excessively, washes hands and face excessively.</i>	0	1	2	3	4
5. Tidying up: Tidying away any objects that have been left out. This may occur in situations when it is inappropriate to put the objects away. Objects may be put away into inappropriate places. <i>E.g. putting cutlery left out for dinner in the bin, removes all objects from surfaces.</i>	0	1	2	3	4
6. Hoarding: Collecting, storing or hiding objects to excess, including rubbish, bits of paper, and pieces of string or any other unusual items.	0	1	2	3	4
7. Organising objects: Organising objects into categories according to various characteristics such as colour, size, or function. <i>E.g. ordering magazines according to size, ordering toy cars according to colour, ordering books according to topic.</i>	0	1	2	3	4
8. Attachment to particular people: Continually asking to see, speak or contact a particular 'favourite' person. <i>E.g. continually asks to see or speak to particular friend, carer, babysitter or schoolteacher.</i>	0	1	2	3	4
9. Repetitive questions: Asking specific questions over and over. <i>E.g. always asking people what their favourite colour is, asking who is taking them to school the next day over and over.</i>	0	1	2	3	4
10. Attachment to objects: Strong preference for a particular object to be present at all times. <i>E.g. carrying a particular piece of string everywhere, taking a particular red toy car everywhere, attachment to soft toy or particular blanket.</i>	0	1	2	3	4

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	Never	Once a month	Once a week	Once a day	More than once a day
11. Repetitive phrases/signing: Repeating particular sounds, phrases or signs that are unrelated to the situation over and over. <i>E.g. repeatedly signing the word 'telephone'.</i>	0	1	2	3	4
12. Rituals: carrying out a sequence of unusual or bizarre actions before, during or after a task. The sequence will always be carried out when performing this task and will always occur in the same way. <i>E.g. turning round three times before sitting down, turning lights on and off twice before leaving a room, tapping door frame twice when passing through it.</i>	0	1	2	3	4
13. Restricted conversation: Repeatedly talks about specific, unusual topics in great detail. <i>E.g. conversation restricted to: trains, buses, dinosaurs, particular film, country or sport.</i>	0	1	2	3	4
14. Echolalia: Repetition of speech that has either just been heard or has been heard more than a minute earlier. <i>E.g. Mum: 'Jack don't do that' Jack: 'Jack don't do that'.</i>	0	1	2	3	4
15. Preference for routine: Insists on having the same household, school or work schedule everyday. <i>E.g. likes to have the same activities on the same day at the same time each week, prefers to eat lunch at exactly the same time every day, wearing the same jumper everyday.</i>	0	1	2	3	4
16. Lining up or arranging objects: Arrangement of objects into lines or patterns. <i>E.g. placing toy cars in a symmetrical pattern, precisely lining up story books.</i>	0	1	2	3	4
17. Just right behaviour: Strong insistence that objects, furniture and toys always remain in the same place. <i>E.g. all chairs, pictures and toys have a very specific place that cannot be changed.</i>	0	1	2	3	4
18. Completing behaviour: Insists on having objects or activities 'complete' or 'whole'. <i>E.g. Must have doors open or closed not in between, story must be read from beginning to end, not left halfway through.</i>	0	1	2	3	4
19. Spotless behaviour: Removing small, almost unnoticeable pieces of lint, fluff, crumbs or dirt from surfaces, clothes and objects. <i>E.g. picking fluff off a jumper, removing crumbs from the kitchen table.</i>	0	1	2	3	4

Please check your answers and go on to the next questionnaire.